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ABSTRACT

Twelve issues of "Exceptional Parent" magazine provide a variety of articles and resources on parenting the child or young adult with a disability. The January issue is a resource guide with directories of national organizations, associations, products, and services. The February issue focuses on early childhood, including assessment, day care, and transitions. The March issue's emphasis is on mobility and considers rehabilitation technology and power/manual wheelchairs. The main topic of the April issue is summer, focusing on vacations, planning, and travel ideas. The May focus is on communication, including facilitated communication, augmentative communication, hearing aids, and using the telephone. The June issue deals with recreation, including the World Games, Special Olympics, and recreation resources. Friendship and community is the featured topic of the July issue. The emphasis of the August issue is on health, including genetic counseling, teaching doctors to communicate, and rhizotomy. The September issue features education, with articles on quality, inclusion, and the Individuals with Disabilities Education Act. October articles are on toy selection, ramps and lifts, and diagnostic labels. Technology is the focus of the November issue. The December issue's emphasis is on family, especially grandparents, estate planning, and the extended family. (DB)

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Exceptional Parent. Volume 25, Numbers 1-12.
Klein, Stanley, Ed.

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JANUARY 1995

EXCEPTIONAL PARENT

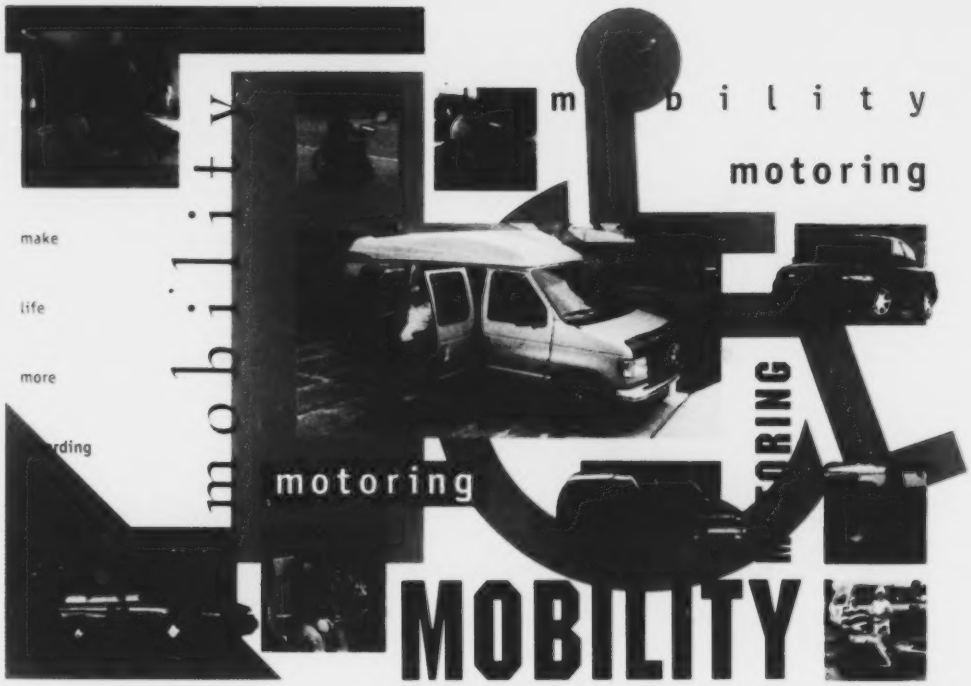
The Magazine for Families and Professionals

1995 RESOURCE GUIDE

DIRECTORIES OF NATIONAL ORGANIZATIONS, ASSOCIATIONS, PRODUCTS & SERVICES

$9.95

3



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EXCEPTIONAL PARENT
Parenting Your Child Or Young Adult With A Disability

Publisher's Letter

Dear Reader and Advertiser,

Thank you! The year 1994 was wonderful for *Exceptional Parent* and it was made possible by you!

As we move into our 24th year, I would like to share some thoughts about the changes taking place in health care and about the impact these changes will have on our readers—the families, health care professionals, and educators that we serve—and on our magazine.

One important change is that today's health care consumers are becoming empowered as never before. Physicians, therapists, nurses, and teachers recognize that they need to *collaborate* with parents. Professionals know they must think of family members who deal with the day-to-day challenges of raising a child or young adult with a disability or special health care need. Moreover, as the number of new treatment therapies increases, so does the need for information to help families and professionals make informed choices and work together more effectively.

Exceptional Parent is moving forward to help meet these needs. You already may have noticed that the inscription inside our logo reads, ***"Parenting Your Child or Young Adult with a Disability,"*** and that our new "tag line" says, ***"The Magazine for Families and Professionals."*** These changes reflect the expanding scope of our magazine. They also point to our commitment to provide even more opportunity for parents, health care professionals, and educators to share ideas and experiences, to learn from one another, and thereby better serve the needs of children and young adults.

For example, our *1995 Annual Resource Guide* contains a new feature. Articles that appeared in 1994 and that are of particular interest to professionals involved in the care and treatment of children and young adults with disabilities or special health care needs are now specifically identified in the Index.

As 1995 begins, we are pleased to point to our efforts to improve communication between the families and professionals we serve. At the same time, we are proud to emphasize that the fundamental mission of ***Exceptional Parent*** remains unchanged. We will continue to offer *Information that Matters, from People Who Care.* This phrase, as always, represents a statement of our purpose and values—what we stand for, who we are and what we do. We will continue to provide information that helps make a difference in the lives of the people we serve. Moreover, all the members of the various departments in our company recognize the importance of what they do. They do it with a passion and sense of caring and commitment that fills me with emotion and an ongoing sense of pride.

To all our readers, please accept my sincere thanks for a gratifying 1994 and my prayers that 1995 will be a wonderful year for you and your children.

Sincerely yours,

Joseph M. Valenzano Jr.
President & Publisher

JANUARY 1995/VOL. 25, ISSUE 1

EXCEPTIONAL PARENT

The Magazine for Families and Professionals

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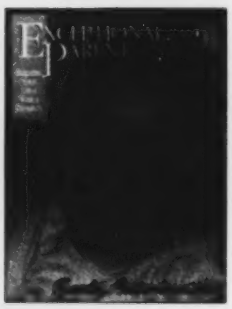

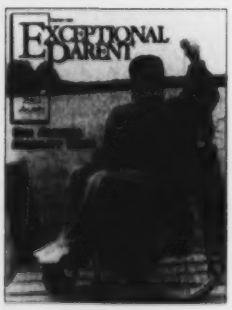

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EDITOR'S DESK

Welcome to our biggest and most comprehensive annual Resource Guide ever! With the help of organizations large and small, this year's guide includes more information about the services each organization provides. We have also included many more Canadian groups.

STANLEY D. KLEIN, PH.D.

We have worked hard to verify all the information in this guide. Nonetheless, we may have made a few errors. Please do not hesitate to contact us with corrections; we will publish all corrections in future monthly issues.

Some organizations are very large and include paid staff members. Others may be coordinated by one or two dedicated volunteers working nights and weekends from a kitchen table. This year's directory includes a few brief stories about several groups to illustrate the energy and creativity of parents everywhere. We know each of the hundreds of groups listed has an equally compelling story.

How to use this Resource Guide

Parents can use the directory of National Resources for Specific Disabilities and Conditions to obtain information about specific conditions and to network with parents of similar children. The extensive cross-referencing may help parents find more than one resource for the same condition or disability.

Sources of local assistance can be identified through Parent Training and Information Centers, Parent to Parent Programs, Alliance for Technology Access Centers and State Assistive Technology Programs. Through these local contacts, parents can communicate with caring people knowledgeable about local resources.

Professionals—physicians, social workers, nurses and educators—can use this guide to put parents in touch with national organizations that can provide emotional support and up-to-date information on specific disabilities or conditions. Professionals can also use these organizations to stay informed and involved. By networking with local groups, professionals can help families and colleagues find nearby resources. Local and national organizations may also help professionals find others who share specific clinical or research interests.

This guide also includes an extensive **index** of topics covered in 1994. To assist professionals, we have marked articles of particular interest to those in the fields of health care and education.

Advertisers

Many companies and service organizations have purchased ads and listings so parents and professionals can find the products and services they need throughout the year. Readers can use the free Product and Service Information cards to obtain detailed information from participating advertisers.

Many years ago, parents and professionals taught us that advertising provides an important service. When *Exceptional Parent* first started to accept advertising—more than 20 years ago—parents and many professionals on a child's clinical or educational team had little say about product purchases. As a result, they were typically excluded from marketing efforts. But today, parents, along with other members of the child's "team," are key decision-makers. Successful companies now appreciate the need to keep parents and professionals well-informed.

Thank you one and all

This guide could not have been completed without the help of many individuals and groups. We are very grateful. And we have been very pleased to hear from so many about how helpful our previous guides have been in making connections throughout the world. We wish you all the best in the new year.

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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 118. BPA International Consumer Magazine Membership Applied for August 1993.

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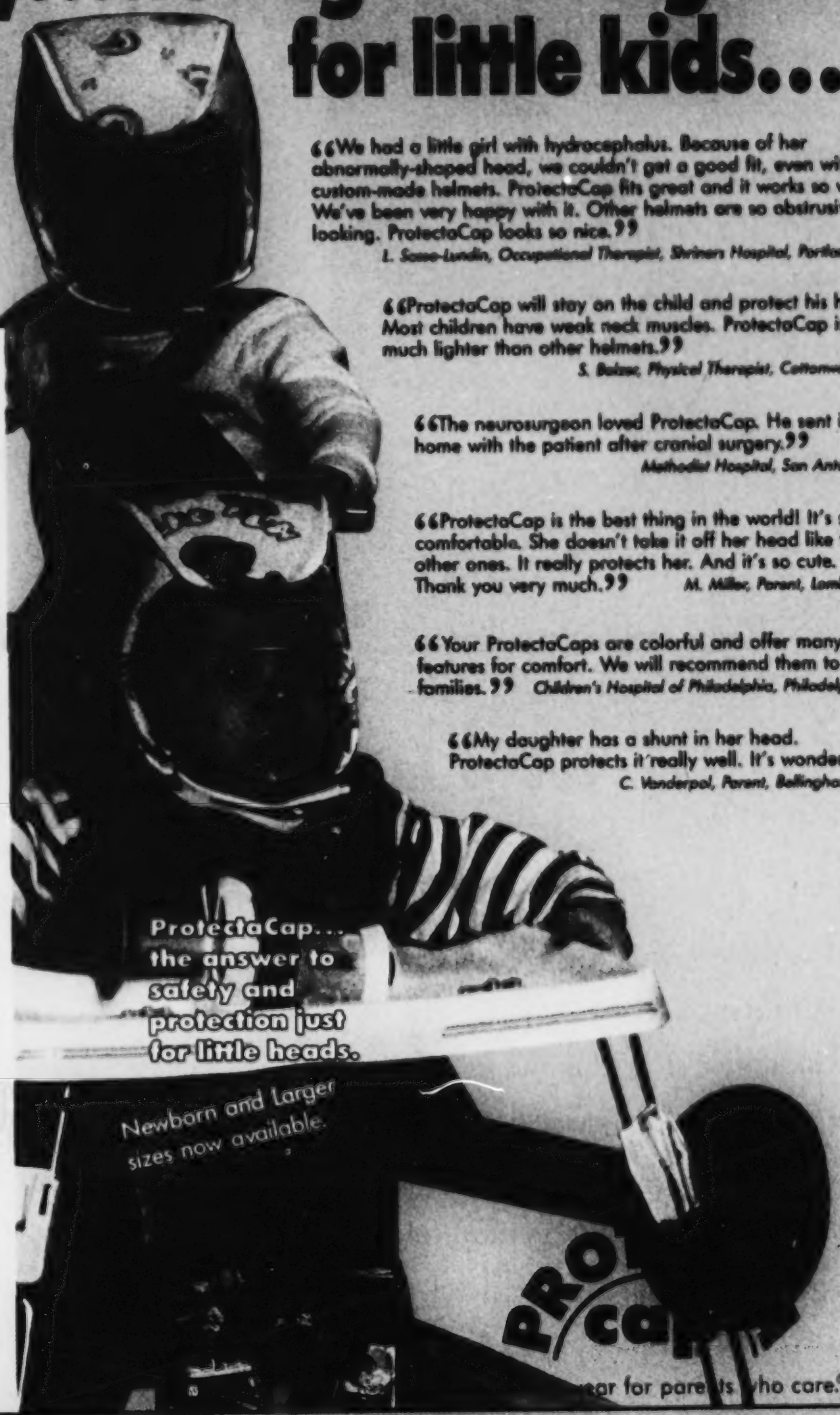

"We had a little girl with hydrocephalus. Because of her abnormally-shaped head, we couldn't get a good fit, even with custom-made helmets. ProtectaCap fits great and it works so well. We've been very happy with it. Other helmets are so obstrusive-looking. ProtectaCap looks so nice."
L. Sasso-Lundin, Occupational Therapist, Shriners Hospital, Portland, OR

"ProtectaCap will stay on the child and protect his head. Most children have weak neck muscles. ProtectaCap is so much lighter than other helmets."
S. Balzer, Physical Therapist, Cottonwood, AZ

"The neurosurgeon loved ProtectaCap. He sent it home with the patient after cranial surgery."
Methodist Hospital, San Antonio, TX

"ProtectaCap is the best thing in the world! It's so comfortable. She doesn't take it off her head like the other ones. It really protects her. And it's so cute. Thank you very much."
M. Miller, Parent, Lombard, IL

"Your ProtectaCaps are colorful and offer many good features for comfort. We will recommend them to our families."
Children's Hospital of Philadelphia, Philadelphia, PA

"My daughter has a shunt in her head. ProtectaCap protects it really well. It's wonderful."
C. Vanderpol, Parent, Bellingham, WA

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National Information and Advocacy Resources

These national organizations are information and advocacy resources for families and professionals. This directory starts with a listing of organizations providing general information and advocacy, followed by organizations focusing on more specific areas of concern to the families of children and adolescents with disabilities.

A description of services provided by individual organizations follows each listing. Numbers correspond to items listed in the Key to Services.

This symbol (✉) indicates an Internet e-mail address.

General

American Association of University Affiliated Programs for Persons with Developmental Disabilities
8630 Fenton St, Ste 410
Silver Spring, MD 20910
(301) 588-8252 (voice)
(301) 588-3319 (TTY)
(301) 588-2842 (fax)
2,5,6,7
• Offers referrals to local University Affiliated Programs which provide technical assistance, training and information to service providers to support the independence, productivity and community inclusion of people with developmental disabilities and their families.

Association for Persons with Severe Handicaps
11210 Greenwood Ave N
Seattle, WA 98133
(206) 361-8870 (voice)
(206) 361-0113 (TTY)
(206) 361-9208 (fax)
1,2,3,4,5,6,7; state and regional chapters
• Advocates for comprehensive, high-quality, integrated education and full participation in inclusive community settings that support the same quality of life available to people without disabilities.

Association of Birth Defect Children
827 Irma Ave
Orlando, FL 32803
(800) 313-2232 (voice, 24-hour registry line)
(407) 245-7035 (voice/fax)
1,3,4,6,7,8
• Offers free parent matching and participation in National Birth Defect Registry. Serves as clearinghouse to provide free information about birth defects, particularly those thought to be associated with exposure to environmental toxins.

Canadian Association for Community Living
4700 Keele St
Kinsman Bldg, York University
North York, ON Canada M3J 1P3
(416) 661-9611 (voice)
(416) 661-2023 (TTY)
(416) 661-5701 (fax)
1,2,5,6,7
• Provides very comprehensive disability-information service. Maintains large book- and video-lending library. Advocates for inclusion and community awareness.

Children's Defense Fund
25 E Street NW
Washington, DC 20001
(800) 233-1200 (voice)
(202) 628-8787 (voice)
(202) 662-3520 (fax)
1,2,3,5,7
• Advocates on behalf of all children, with particular attention to the needs of children who are economically disadvantaged, have disabilities or are members of minority groups. Focus is on programs that affect large numbers of children rather than on helping individual families.

DIRECT LINK for the disABLED
PO Box 1036
Solvang, CA 93464
(805) 688-1603 (V/TTY)
(805) 686-5285 (fax)
1,2,3,4,6
• Provides information and education to people seeking help for any disability- or health-related question. Services provided at no charge to individuals and families.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave
White Plains, NY 10605
(914) 428-7100 (voice)
(914) 428-8203 (fax)
6,7,8
• Provides referrals to specialty health care providers, genetic counselors and support groups across the country. Provides educational information on birth defects, genetics and prenatal care.

National Center for Youth with Disabilities
University of Minnesota
Box 721
420 Delaware St SE
Minneapolis, MN 55455
(800) 333-6293 (voice)
(612) 626-2825 (voice)
(612) 624-3939 (TTY)
(612) 626-2134 (fax)
✉ ncyd@gold.tc.umn.edu
1,2,5,7
• Provides information and technical assistance on issues affecting adolescents with chronic illnesses and disabilities and the transition to adult life.

National Easter Seal Society
230 W Monroe
Chicago, IL 60606
(312) 726-6200 (voice)
(312) 726-4258 (TTY)
(312) 726-1494 (fax)
✉ eseals@mcs.com
2,3,6,7; disability-awareness curriculum for elementary schools
• Affiliates in 500 service locations provide physical and occupational therapy, audiology, camping, recreation, early intervention and vocational programs for children, teens and their families.

Key to Services

1. **Periodical/newsletter**
2. **Other publications**
3. **Videos**
4. **Networking/matching with other families**
5. **National conferences**
6. **Referrals to local resources**
7. **National advocacy efforts**
8. **Fund research**
9. **Provide electronic computer bulletin board**

National Organization on Disability
910 16th St NW, Ste 600
Washington , DC 20006
(800) 248-2253 (voice)
(202) 293-5968 (TTY)
(202) 293-7999 (fax)
1,2,3,6,7
• Promotes public awareness and supports legislation to improve the lives of people with disabilities. Does not provide any direct services to families.

NPND: National Parent Network on Disabilities
1600 Prince St, Ste 115
Alexandria, VA 22314
(703) 684-6763 (V/TTY)
(703) 836-1232 (fax)
1,2,3,5,6,7
• Provides a national presence and voice for parents of children, youth and adults with disabilities. Shares information and resources to promote the power of parents to influence government policy relating to the needs of people with disabilities and their families.

NATIONAL INFORMATION AND ADVOCACY RESOURCES

National Vaccine Information Center—Dissatisfied Parents Together
512 W Maple Ave, #206
Vienna, VA 22180
(703) 938-3783 (voice)
(703) 938-5768 (fax)
1,2,3,4,7
• *Advocates for the prevention of vaccine reactions. Provides information on the Vaccine Injury Compensation Program. Makes legal referrals.*

NICHCY: National Information Center for Children and Youth with Disabilities
PO Box 1492
Washington, DC 20013
(800) 695-0285 (V/TTY)
(202) 854-8200 (V/TTY)
(202) 884-8441 (fax)
nichy@capcon.net
1,2,4,6; many publications available in Spanish
• *Collects and shares information and ideas that are helpful to children and youth with disabilities and the people who care for and about them. Answers questions, links people with others who share common concerns and helps information flow between people who have it and people who need it. Single copies of all publications are free.*

Rural Institute on Disabilities
52 Corbin Hall
University of Montana
Missoula, MT 59812
(800) 732-0323 (V/TTY)
(406) 243-5467 (V/TTY)
(406) 243-4730 (fax)
1,2,6,9 (800/961-9610, up to 9600 baud)
• *Provides information and referral, lending library of books and videotapes, assistance to children of Vietnam veterans and assistive technology loan/lease program.*

STOMP: Specialized Training of Military Parents
c/o Washington PAVE
12208 Pacific Highway SW
Tacoma, WA 98499
(800) 298-3543 (voice)
(206) 588-1741 (V/TTY)
(206) 984-7520 (fax)
1,2,4,6
• *Provides information about parental rights and responsibilities in obtaining special educational services for children of military personnel. Provides information about testing and assessment, IEPs and networking with military resources.*

World Institute on Disability
510 16th St, Ste 100
Oakland, CA 94612-1502
(510) 763-4100 (V/TTY)
(510) 7208-9493 (TTY)
(510) 763-4109 (fax)
wid@wid.org
1,2,6,7
• *Public policy, research and training center dedicated to independence for all people with disabilities. Seeks to provide accurate information for public and private policymakers to use in crafting services and policies that support independence and quality of life. Does not provide direct client services.*

Adoption

AASK: Adopt a Special Kid
2201 Broadway, Ste 702
Oakland, CA 94612
(510) 451-1748 (voice)
(510) 451-2023 (fax)
1,4,6,7
• *Adoption agency specializing in the placement of children with disabilities; sliding-scale fee for services. Provides post-adoption support services.*

Adoptive Families of America
3333 Highway 100N
Minneapolis , MN 55422
(800) 372-3300 (voice)
(612) 535-4829 (voice)
(612) 535-7808 (fax)
1,2,3,4,5,6,7
• *Provides problem-solving assistance and information to members of adoptive families and prospective adoptive families. Promotes the health and welfare of children without permanent families.*

Jewish Children's Adoption Network
PO Box 16544
Denver, CO 80216-0544
(303) 573-8113 (voice)
(303) 893-1447 (fax)
1,4,6
• *Helps both birth and adoptive families find resources to help them parent children with disabilities. Finds adoptive placements for waiting children.*

National Adoption Center
1500 Walnut St, Ste 701
Philadelphia, PA 19102
(800) 862-3678 (voice)
(215) 735-9988 (voice)
(215) 735-9410 (fax)
4
• *Approved adoptive families may register on National Adoption Exchange, a computerized database of waiting minority children and children with disabilities and families hoping to adopt such a child.*

National Resource Center for Special Needs Adoption
16250 Northland Dr, Ste 120
Southfield, MI 48075
(810) 443-7080 (voice)
(810) 443-7099 (fax)
1,2,3,5,6,7,8
• *Provides a forum for adoption practitioners, policymakers and advocates to share knowledge and expertise. Serves as a resource for organizations and professionals through consultation, technical assistance, training and a variety of written and videotaped materials.*

Architectural Accessibility

Center for Universal Design
North Carolina State University
School of Design
Box 8613
Raleigh, NC 27695-8613
(800) 647-6777 (V/TTY, US & Canada)
(919) 515-3082 (V/TTY)
(919) 515-3023 (fax)
1,2,6
• *Provides design information and assistance to families and individuals with disabilities for construction of new housing and home modifications.*

Assistive Technology

Access Unlimited
3535 Briarpark Dr, Ste 102
Houston, TX 77042
(800) 848-0311
(713) 781-7441
(713) 781-3550 (fax)
1,6
• *Resource center for information on assistive technology.*

Key to Services

1. **Periodical/newsletter**
2. **Other publications**
3. **Videos**
4. **Networking/matching with other families**
5. **National conferences**
6. **Referrals to local resources**
7. **National advocacy efforts**
8. **Fund research**
9. **Provide electronic computer bulletin board**

Activating Children Through Technology
27 Horrabin Hall
Western Illinois University
Macomb, IL 61455
(309) 298-1014 (voice)
(309) 298-2305 (fax)
mflmr@uxa.ecn.bgu.edu
1,2,3,5
• *Provides training and resource information to families of children, birth to eight years, on integrating technology into individual educational programs (IEPs).*

Child Care

Child Care Plus
Rural Institute on Disabilities
52 N Corbin Hall
University of Montana
Missoula, MT 59812
(800) 235-4122 (V/TTY)
(406) 243-5467 (V/TTY)
(406) 243-4730 (fax)
1,2,5,6
• *Provides technical assistance, written materials and training for families, child care providers and others who support inclusion in early childhood programs.*

SpeciaLink
186 Prince St
Sydney, NS Canada B1P 5K5
(800) 840-5465 (voice, Canada only)
(902) 562-1662 (voice)
(902) 539-9117 (fax)
sirwin@fox.nstn.ca
1,2,3,4,5,6,7
• *Serves as the hub of a 3,000-person network of advocates for inclusive child care and education. Provides resources and referrals. Promotes inclusive practices, policies and programs across Canada.*

NATIONAL INFORMATION AND ADVOCACY RESOURCES

Education

National Coalition of Title I/Chapter I Parents
Edmonds School Bldg, Rm 201
9th & D St NE
Washington, DC 20002
(202) 547-9286 (voice)
(202) 544-2813 (fax)
1,3,5,6,7; scholarship program
• Provides information, training and technical assistance to parents to help them participate in planning, implementing and evaluating local Title I programs.

Employment

Electronic Industries Foundation Project with Industry
919 18th St NW, Ste 900
Washington, DC 20006
(202) 955-5815 (voice)
(202) 955-5836 (TTY)
(202) 955-5837 (fax)
6
• Provides job placement for persons with disabilities; provides referrals and job-matching services to employers.

Job Accommodation Network
West Virginia University
Morgantown, WV 26506-6080
(800) 232-9675 (V/TTY)
(800) 526-7234 (V/TTY)
(800) 526-2262 (V/TTY; from Canada)
2,3,6,9 (800/342-5526, up to 9600 baud)
• Provides information about job accommodations, the employability of people with functional limitations and the Americans with Disabilities Act (ADA).

Job Opportunities for the Blind
National Center for the Blind
1800 Johnson St
Baltimore, MD 21230
(800) 638-7518 (voice)
(410) 659-9314 (voice)
(410) 685-5653 (fax)
1,2,5,6,7
• Free information packet. Shares methods and ideas that have helped other blind workers get good jobs. Nationwide networking, reference and referral services.

National Industries for the Severely Handicapped
2235 Cedar Ln
Vienna, VA 22182
(703) 560-6800 (voice)
(703) 849-8916 (fax)
1,2,3,5,6,7
• Provides technical assistance to local rehabilitation providers about employment of people with severe disabilities.

Genetics

Hereditary Disease Foundation
1427 7th St, Ste 2
Santa Monica, CA 90401
(310) 458-4183 (voice)
(310) 458-3937 (fax)
75051.3604@compuserve.com
2,3,4,6,7,8
• Supports biomedical research. Focuses on Huntington's disease, but can refer families to support groups for other disorders.

Health Care

Association for the Care of Children's Health
7910 Woodmont Ave, Ste 300
Bethesda, MD 20814
(800) 808-2224, ext 306 (voice)
(301) 654-6549, ext 306 (voice)
(301) 986-4553 (fax)
ACCH@clark.net
1,2,3,4,5,6,7,8
• Organization of family members and multidisciplinary professionals. Advocates for family-centered care for children needing specialized health and developmental services. Offers a forum for information sharing and peer support.

Children's Hospice International
700 Princess St, Lower Level
Alexandria, VA 22314
(800) 242-4453 (voice)
(703) 684-0330 (voice)
(703) 684-0226 (fax)
1,2,3,4,5,6,7

Family Voices
Box 769
Algodones, NM 87001
(505) 867-2368 (voice)
(505) 867-6517 (fax)
1,2,7
• National grassroots network of families with children who have special care needs. Gathers, analyzes and provides information on state and national health care reform from a family perspective.

Parent Care
9041 Colgate St
Indianapolis, IN 46268-1210
(317) 872-9913 (voice)
(317) 872-0795 (fax)
1,2,4,5,6
• Advocates for family-centered services and provides social, emotional and informational support to families and caregivers involved in neonatal intensive care.

The Center for Children with Chronic Illness and Disability
University of Minnesota
Box 721 UMHC
420 Delaware St SE
Minneapolis, MN 55455
(612) 626-4032 (voice)
(612) 624-3939 (TTY)
(612) 626-2134 (fax)
c3id@gold.pc.umn.edu
1,2,3,6,7
• Seeks to increase and apply knowledge that fosters the physical, psychological and social development and competence and well-being of infants, children and adolescents with chronic illnesses and disabilities and their families.

Independent Living

Independent Living Research Utilization Program
2323 S Shepherd, Ste 1000
Houston, TX 77019
(713) 520-0232 (voice)
(713) 520-5136 (TTY)
(713) 520-5785 (fax)
1,2,3,6,7
• Collects, synthesizes and disseminates information on independent living (IL) subjects. Maintains directories of IL centers, of people who provide IL technical assistance and of IL support materials.

Legal Assistance

American Bar Association Center on Children and the Law
1800 M St NW, Ste 200 S
Washington, DC 20036
(202) 331-2250 (voice)
(202) 331-2250 (fax)
davidsonha@attmail.com
2
• Publishes information about legal issues related to children.

DREDF: Disability Rights Education and Defense Fund
2212 Sixth St
Berkeley, CA 94710
(800) 466-4232 (V/TTY)
(510) 644-2555 (V/TTY)
(510) 841-8645 (fax)
1,3,6
• National law and policy center dedicated to furthering the civil rights of people with disabilities. Offers training, information and legal advocacy to parents of children with disabilities to help them secure appropriate educational and other services. Offers technical assistance, information and referrals by phone.

National Association of Protection and Advocacy Systems
900 2nd St NE, Ste 211
Washington, DC 20002
(202) 408-9514 (voice)
(202) 408-9521 (TTY)
(202) 408-9520 (fax)
HN4537@handsnet.org
1,5,6,7
• Voluntary membership organization of federally-mandated programs advocating for the rights of people with disabilities. Offers referral to programs in each state and territory.

National Center for Law and Deafness
Gallaudet University
800 Florida Ave NE
Washington, DC 20002
(202) 651-5373 (V/TTY)
(202) 651-5381 (fax)
2,6,7
• Develops and provides a variety of legal services and programs to the Deaf community, including representation, counseling, information and education.

Pike Institute on Law and Disability
Boston University School of Law
765 Commonwealth Ave
Boston, MA 02215-1620
(617) 353-2904 (V/TTY)
(617) 353-2906 (fax)
hbeyer@bu.edu
1,5,6
• Provides information and referrals in disability-related legal matters. Publishes bi-monthly DISABILITY ADVOCATES BULLETIN.

NATIONAL INFORMATION AND ADVOCACY RESOURCES

Rare Disorders

Alliance of Genetic Support Groups
35 Wisconsin Cir, Ste 440
Chevy Chase, MD 20815-7015
(800) 336-4363 (voice)
(301) 652-5553 (voice)
(301) 654-0171 (fax)
1,2,4,5,7
• *Serves as a forum for addressing the needs of individuals and families affected by genetic disorders and as a bridge between consumers and service providers.*

Lethbridge Society for Rare Disorders
#2 740 4th Ave S
Lethbridge, AB, Canada T1J 0N9
(403) 329-0665 (voice)
1,4,5,6
• *Offers networking services and local referrals to people with rare disorders and their families.*

MUMS: Mothers United for Moral Support
c/o Julie Gordon
150 Custer St
Green Bay, WI 54301
(414) 336-5333 (voice)
(414) 339-0995 (fax)
1,4
• *National parent-to-parent network matches parents with others whose children have similar rare disorders or conditions.*

NORD: National Organization for Rare Disorders
100 Rt 37, PO Box 8923
New Fairfield, CT 06812-8923
(800) 999-6673 (voice)
(203) 746-6518 (voice)
(203) 746-6927 (TTY)
(203) 746-6481 (fax)
1,2,4,5,8
• *Clearinghouse for information about rare disorders. Provides literature explaining disorders (first two disease reports free; $4 each thereafter) and offers networking of families with similar disorders (for paid members only).*

Rehabilitation

Canadian Rehabilitation Council for the Disabled
45 Sheppard Ave E, Ste 801
Willowdale, ON, Canada M2N 5W9
(416) 250-7490 (V/TTY)
(416) 229-1371 (fax)
1,2,3,4,5,6,7
• *Umbrella organization of Canadian service providers, health professionals and consumer groups. Offers publications, disability-awareness materials and other resources.*

Since this photo was taken, 11-year-old Joey Bishop of Aromore, Oklahoma has learned to float without any help from Mom or his inflatable aids. Aside from his aquatic pursuits, Joey enjoys watching movies and baseball, driving his power wheelchair, going out to eat and talking to people using his augmentative communication device. Joey, a seventh-grader, says math and "girls" are his best subjects. Joey has agenesis of the corpus callosum.

Respite Care
ARCH National Resource Center
800 Eastowne Dr, Ste 105
Chapel Hill, NC 27514
(800) 773-5433 (voice)
(919) 490-4905 (fax)
• *Free national respite-provider locator service through 800-number listed above.*

Self-Help

American Self-Help Clearinghouse
St. Clares-Riverside Medical Ctr
6 Hinchman Ave
Denville, NJ 07834
(201) 625-9565 (voice)
(201) 625-8848 (fax)
edmadara@aol.com
2,4,6
• *Provides referrals to support groups and other self-help clearinghouses. Provides information on starting support groups.*

National Self-Help Clearinghouse
CUNY Grad School, University Ctr
25 W 43rd St, Rm 620
New York, NY 10036
(212) 354-8525 (voice)
(212) 642-1956 (fax)
edmadara@aol.com
1,2
• *Provides referrals to support groups and other self-help clearinghouses. Provides information on starting support groups and outreach to the public and professionals.*

Sexuality

Sex Information and Education Council of the US
130 W 42nd St, Ste 2500
New York, NY 10036-7901
(212) 819-9770 (voice)
(212) 819-9776 (fax)
1,2,6
• *Library has 5,000 volumes and more than 10,000 indexed articles on sexuality. Collects extensively in the area of sexuality and disability. Does database searches to find books and articles of interest.*

Sibling Support

Sibling Information Network
The A.J. Pappanikou Center on Special Education and Rehabilitation
62 Washington St
Middletown, CT 06457
(203) 648-1205 (voice)
(203) 644-2031 (fax)
1,2
• *Clearinghouse of information related to siblings of individuals with disabilities.*

Key to Services

1. **Periodical/newsletter**
2. **Other publications**
3. **Videos**
4. **Networking/matching with other families**
5. **National conferences**
6. **Referrals to local resources**
7. **National advocacy efforts**
8. **Fund research**
9. **Provide electronic computer bulletin board**

Sibling Support Project
PO Box 5371, CL-09
Seattle, WA 98105-0371
(206) 368-4911 (voice)
(206) 368-4816 (fax)
1,2,6,7
• *Creates materials and provides training and technical assistance for organizing peer-support and education programs for siblings of people with disabilities. Conducts workshops throughout the US for family members and service providers.*

Travel

Mobility International USA
PO Box 10767
Eugene, OR 97440
(503) 343-1284 (V/TTY)
(503) 343-6812 (fax)
miufa@igc.apc.org
1,2,3,4,6,7
• *Provides international educational, travel and leadership development opportunities for youths and adults with disabilities. Coordinates educational exchanges with other countries. Offers travel information and referral services for people with disabilities and their families.*

Travel Information Service
Moss Rehab Hospital
1200 W Tabor Rd
Philadelphia, PA 19141
(215) 456-9600 (voice)
(215) 456-9602 (TTY)
6,7
• *Provides free telephone information on travel accessibility to people with physical disabilities and their families.*

13

International Leader in Personal Mobility Products

The Braun Corporation has established their products as the benchmark for International Personal Mobility. The new Lift-A-Way D/C® continues Braun's reputation for dependability and excellence.

Braun's nonskid yellow ARS (Automatic Roll Stop) engages before any vertical platform movement. Boasting the lowest loading ramp angle in the industry, the ARS makes it easy to load both power and manual wheelchairs onto the platform.

Dual locking handrails contribute to a secure environment while on the lift platform. Other safety features include yellow demarcation of the wheelchair loading boundaries and an override circuit which prevents the Lift-A-Way D/C® from folding when there is weight on the platform.

No matter what your needs, Braun has a mobility system designed for you. The original Lift-A-Way® platform lift is a reliable performer proven with over two decades of use. For greater convenience and cargo access, we offer the Entry-A-Way®. The lowest floor traverse® is the perfect choice for the individual or small family. And, for the person who requires the Braun Chair Tipper®, conveniently access a conventional folding wheelchair out of your way.

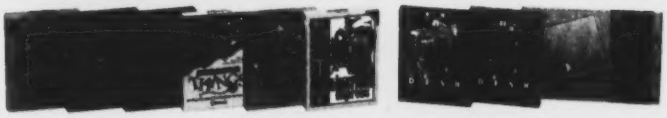
The Braun Corporation. Mobility at its best.

Wonder. Discovery. Delight.

We cover the basics.

Edmark software does more than teach kids about math, reading and science. Our programs *delight* them—with colorful graphics, children's voices and *lots* of humor. Positive feedback and visual and auditory cues gently guide them to success. Using the optional TouchWindow, they can interact directly with the software simply by touching the screen.

For more information and a free product catalog, call **1-800-320-8380**.



Winner of 53 Awards!

Millie's Math House, Bailey's Book House, Sammy's Science House (PreK–2nd Grade), Thinkin' Things Collections 1 and 2, Imagination Express, KidDesk (PreK–6th Grade), and the TouchWindow. Available for Macintosh and WIN/DOS computers.

Edmark software features built-in single switch scanning.

EDMARK

15456) 12/94

Circle # 109

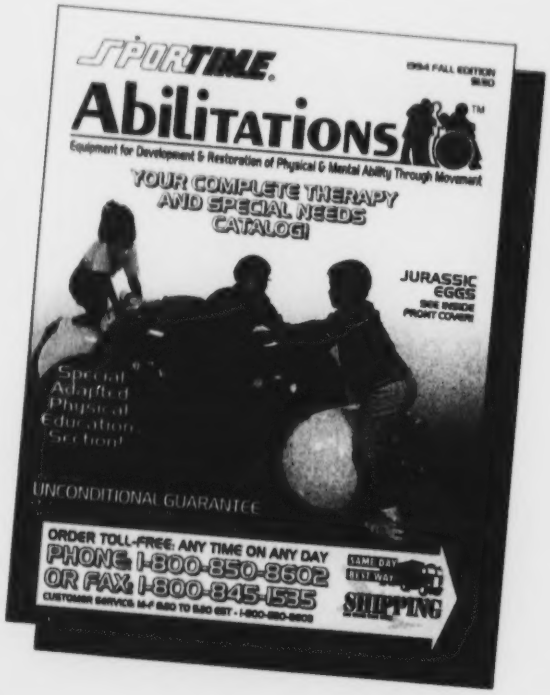
Abilitations™

Available from Sportime® International

Sportime International, a well-known leader in manufacturing and designing movement products since 1966, can offer you therapeutic equipment for your children and adults alike. Whether you're in need of equipment for encouraging movement, positioning, exercise, sensory-activities or augmentation, Abilitations can provide you and your special someone with equipment of the highest quality.

PHYSIO-ROLL Like most of our products, our own patented Physio-Roll is designed with the highest quality of rotational molding available. Physio-Rolls are the ideal medium for balance training, strengthening and proprioceptive activities. Their unique shape provides the mobility of a ball with the stability of a bolster. Physio-Rolls are available in 5 different sizes from 30cm to 85cm in traditional colors or clear. Also available are Physio-Roll-R-Cise Cards for home exercise education.

For more information on Physio-Rolls or to receive any of Sportime International's FREE catalogs, call 1-800-850-1535.



15

Circle # 22

A U N

New
Out

The Perfect Companion

The Braun Companion Seat®

If you have difficulty entering and exiting your vehicle, the new Companion Seat® is your key to greater mobility. Its automatic operation and rugged construction enable semi ambulatory persons to reliably and conveniently board Dodge Caravan or Plymouth Voyager minivans.

The seat extends 20" and tilts forward a full 6" to make boarding safe and easy. Once on the seat, you are smoothly raised into the vehicle by pressing the conveniently mounted switch. All you have left to do is manually rotate into the forward facing position. To exit, the procedure is simply reversed.

The Companion Seat® utilizes your van's original seat, but replaces the existing seat base with a unique power base. When not needed, it functions exactly as the passenger seat. This innovative design is perfect for active families with only one member who needs assistance. And, as always, Braun thoroughly tested the Companion Seat® to meet all applicable federal motor vehicle safety standards.

If you need financial assistance, Chrysler offers cash rebates towards the purchase of adaptive equipment through the Chrysler Corporation Automobility Program. Ask your local Braun distributor about other sources of assistance.

For more information on the Companion Seat® or other Braun mobility products, call us today at 1-800-THE LIFT. We will give you the name and location of distributors in your area.

Now more than ever, mobility is one of the most important things in your life. Let Braun and the Companion Seat® be the answer to your needs.

Patents Pending

THE BRAUN CORPORATION

"Providing Access to the World"

1-800-THE LIFT

The Braun Corporation is the international leader in mobility products. With four divisions and a worldwide distributor network, we are positioned to provide the equipment and services you need. Our commitment to your satisfaction is also supported by our Three-Year Worry-Free Limited Warranty. Simply call 1-800-THE-LIFT for the Braun dealer nearest you.

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kid-kart™
cares about kids.

kid-EZ tilt/recline™

made in USA
PATENT PENDING

NOW FEATURING A
Bus Transport Model

kid-EZ Adjustable High Chair Base

- Three Models
- Grows from infant to age 7
- Complete Positioning System

Easy to fold
Easy to transfer
Easy to adjust

1-800-388-5278
732 Cruiser Lane
Belgrade, Montana
59714

Circle # 98

Columbia makes bathtime easier!
- Stable, secure Bath Supports adjust easily to suit you and your child; fit any tub
- All are durable, lightweight, rustproof
- Versatile – use indoors or outdoors as a go-anywhere support, for TV, wading pool, beach

How much support?
- The Wrap-around Support (above) lets your child play in the water while seated upright
- The Reclining Bath Chair (below) gives your child full-length head and trunk support; the angle of the seat is easily adjustable

Ask for our FREE Color Catalog of many helpful products. We'll also send the name of your nearest dealer.

COLUMBIA

17

Circle # 151

A scientific breakthrough in dental hygiene

THE AUTOMATIC TOOTHBRUSH

ORALGIENE™

The Science of Oral Hygiene

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Circle # 184

Bed-wetting won't bother him tonight. And you can't see why.

Pull-Ups® GoodNites™ absorbent underpants are the first ones ever made for bigger children–45 pounds and up.

They're superabsorbent, yet so thin, they all but disappear under pajamas.

The child slips them on and–accident or not–wakes in a clean, dry bed. With a whole new positive attitude.

GoodNites™ will help keep kids dry until they outgrow bed-wetting. Since 3 million kids share this problem, that's a lot of good mornings.

Get the GoodNites™ Guide for Kids–yours for sending just $1 postage and handling to: GoodNites™ Book Offer, P.O. Box 1125, Maple Plain, MN 55592.

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"GoodNites™ mean Good Mornings."

Circle # 133

National Resources for Specific Disabilities and Conditions

This directory includes national groups and organizations that can serve as resources for parents and professionals seeking information and support regarding specific disabilities and conditions. Where appropriate, disability categories have been cross-referenced to enable readers to find other relevant resources for a specific disability or condition. Where appropriate, several entries in this directory also appear in other directories within this volume.

A description of services provided by individual groups follows each listing. Numbers correspond to items listed in the Key to Services. This symbol (📧) indicates an Internet e-mail address. Unless otherwise indicated, telephone numbers are for voice only.

A-Beta-Lipoproteinemia

See: Tay-Sachs Disease

Aarskog Syndrome

See also: Growth Disorders

Aarskog Syndrome Parent Support Group
c/o Shannon Caranci
62 Robin Hill Ln
Levittown, PA 19055-1411
(215) 943-7131
1,4,10

Acid Maltase Deficiency

See: Muscular Dystrophy

Acidemia, Organic

See also: Maple Syrup Urine Disease, Neurometabolic Disorders

Organic Acidemia Association
c/o Carol Barton
2287 Cypress Ave
San Pablo, CA 94806
(510) 724-0297
1,4,5,10

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

Acoustic Neuroma

See also: Balance Disorders & Dizziness, Hearing Impairments, Neurofibromatosis, Vestibular Disorders

Acoustic Neuroma Association
PO Box 12402
Atlanta, GA 30355
(404) 237-8023
(404) 237-2704 (fax)
1,2,3,4,5,6,10

Acoustic Neuroma Association of Canada
PO Box 369
Edmonton, AB CAN T5J 2J6
(800) 561-2622 (V/TTY, Canada)
(403) 428-3384 (V/TTY)
1,2,3,4,5,6,7,8

Addison Disease

See: Adrenal Disorders; Adrenal Hyperplasia, Congenital

Adrenal Disorders

See also: Adrenal Hyperplasia, Congenital

National Adrenal Disease Foundation
505 Northern Blvd
Great Neck, NY 11021
(516) 487-4992
1,2,4,5

Adrenal Hyperplasia, Congenital

See also: Growth Disorders

Congenital Adrenal Hyperplasia Support Association
801 County Rd, #3
Wrenshall, MN 55797
(218) 384-3863
2,4,7,10

Adrenoleukodystrophy

See: Leukodystrophy

Adrenoleukodystrophy, Neonatal

See: Leukodystrophy

Agenesis of the Corpus Callosum

ACC Network
86 N Main St
Orono, ME 04473
(207) 866-2062
(207) 581-3119
(207) 581-3120 (fax)
📧 RHD351@maine.maine.edu
1,2,4,10

Agyria

See: Lissencephaly

Aicardi Syndrome

Aicardi Syndrome Awareness and Support Group
29 Delavan Ave
Toronto, ON CAN M5P 1T2
(416) 481-4095
4

Aicardi Syndrome Newsletter
5115 Troy Urbana Rd
Casstown, OH 45312
(513) 339-6033 (voice/fax)
1,2,4,6,7,8,10

AIDS

CDC National AIDS Hotline
American Society Health Assn
PO Box 13827
Research Triangle Park, NC 27709
(800) 342-2437
(800) 344-7432 (Spanish)
(800) 243-7889 (TTY)
2,7

National Pediatric HIV Resource Center
15 S 9th St
Newark, NJ 07107
(800) 362-0071
(201) 268-8251
(201) 485-2752 (fax)
1,2,3,4,6,7,8,9; school nurse educational program

Alagille Syndrome

See also: Liver Disorders

Alagille Syndrome Alliance
10630 SW Garden Park Pl
Tigard, OR 97223
(503) 639-6217
1,4,10

Albinism & Hypopigmentation

See also: Visual Impairments

National Organization for Albinism and Hypopigmentation
1530 Locust St, #29
Philadelphia, PA 19102
(800) 473-2310
1,2,5,6,8

Alexander's Disease

See: Leukodystrophy

Allergy

See: Asthma & Allergy

Alopecia Areata

National Alopecia Areata Foundation
710 C St, Ste 11
San Rafael, CA 94901
(415) 456-4644
(415) 456-4274 (fax)
📧 74301.1642@compuserve.com
1,2,3,4,5,6,7,8,9

Alstrom Syndrome

See also: Diabetes Mellitus, Hearing Impairments, Visual Impairments

Alstrom Syndrome Newsletter
1006 Howard Rd
Warminster, PA 18974
1,10

Alternating Hemiplegia

See: Hemiplegia, Alternating

Amputation

See also: Limb Disorders

American Amputee Foundation
PO Box 250218
Little Rock, AR 72225
(501) 666-2523
(501) 666-8367 (fax)
1,2,3,5,7

National Amputation Foundation
73 Church St
Malverne, NY 11565
(516) 887-3600
(516) 887-3667 (fax)
1,2,4,7

Anderson Disease

See: Glycogen Storage Disease

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Anemia, Aplastic

Aplastic Anemia Foundation of America
PO Box 22689
Baltimore, MD 21203
(800) 747-2820
1,2,4,5,6,7,8,9,10

Anemia, Cooley's

See: Cooley's Anemia

Anemia, Fanconi

See also: Leukemia

Fanconi Anemia Research Fund/Support Group
1902 Jefferson, #2
Eugene, OR 97405
(503) 687-4658
(503) 687-0548 (fax)
1,2,4,5,6,8,9

Anemia, Hemolytic

See: Evans Syndrome

Angelman Syndrome

Angelman Syndrome Foundation
PO Box 12437
Gainesville, FL 32604
(904) 332-3303
1,3,4,6,9,10

Canadian Angelman Syndrome Society
PO Box 37
Priddis, AB CAN T0L 1W0
(403) 931-2415 (voice/fax)
1,2,4,6,10; liaison with groups in other countries

Aniridia

See: Visual Impairments

Ankylosing Spondylitis, Juvenile

See: Arthritis

Anophthalmia

See: Visual Impairments

Anorectal Malformations

See also: Intestinal Pseudo-Obstruction Syndrome

Pull-Thru Network
1 Circle Rd
Darien, CT 06820
(203) 655-6288
(201) 891-5932
1,4,10

Apert Syndrome

See also: Craniofacial Disorders

Apert Syndrome Pen Pal Network
PO Box 115
Providence, RI 02901
(401) 421-9076
4,7

Aphasia, Acquired

National Aphasia Association Young People's Network
PO Box 1887
Murray Hill Station
New York, NY 10156-0611
(800) 922-4622
1,4,7

Apiastic Anemia

See: Anemia, Aplastic

Apraxia

See also: Language Disorders, Learning Disabilities

National Organization for Apraxia and Dyspraxia
30660 Milky Wy Dr, Ste I-66
Temecula, CA 92592
(909) 695-9446
1,2,4,7,10

Aqueductal Stenosis

See: Hydrocephalus

Arginase Deficiency

See: Urea Cycle Disorders

Argininosuccinic Aciduria

See: Urea Cycle Disorders

Arnold-Chiari Malformation

See also: Spina Bifida, Syringomyelia

Arnold-Chiari Family Network
c/o Maureen & Kevin Walsh
67 Spring St
Weymouth, MA 02188
(617) 337-2368
2,4

Arteriovenous Malformations (AVMs)

See: Vascular Malformations

Arthritis

American Juvenile Arthritis Organization
1314 Spring St NW
Atlanta, GA 30309
(800) 283-7800
(404) 872-7100
(404) 872-0457 (fax)
pharring@arthritis.org
1,2,3,4,5,6,7,8,9; partnership training program for parents and health care providers

Arthritis Society
250 Bloor St, Ste 901
Toronto, ON CAN M4W 3P2
(800) 361-1112 (Ontario only)
(416) 967-1414
(416) 967-7171 (fax)
1,2,3,4,5,8,9

Arthrogryposis Multiplex Congenita

See also: Growth Disorders

AVENUES: A National Support Group for Arthrogryposis Multiplex Congenita
PO Box 5192
Sonora, CA 95370
(209) 928-3688
1,2,4,6,7,10

CAST: Canadian Arthrogryposis Support Team
365 Fiddler's Green Rd S
Ancaster, ON CAN L9G 1X2
(209) 928-3688
1,3,4,5,7,10

Asperger Syndrome

See: Autism

Asthma & Allergy

See also: Lung Diseases

Allergy/Asthma Association
30 Eglinton Ave W, Ste 750
Mississauga, ON CAN L5R 3E7
(905) 712-2242
(905) 712-2245 (fax)
1,2,3,4,5,6,8

Asthma and Allergy Foundation of America
1125 15th St NW, Ste 502
Washington, DC 20005
(800) 727-8462
(202) 466-7643
(202) 466-8940 (fax)
1,5,7,8,9,10

Ataxia

National Ataxia Foundation
750 Twelve Oaks Ctr
15500 Wayzata Blvd
Wayzata, MN 55391
(612) 473-7666
(612) 473-9289 (fax)
1,4,5,6,7,9

Ataxia Telangiectasia

See also: Autoimmune Disorders, Immune Disorders

Ataxia Telangiectasia Children's Project
21646 Cartagena Dr
Boca Raton, FL 33428
(407) 483-2661
1,4,5,6,7,8,9,10

Atresia

See: Microtia

Attention Deficit Disorder

See also: Learning Disabilities

Attention Deficit Disorder
AD-IN: Attention Deficit Information Network
475 Hillside Ave
Needham, MA 02194
(617) 455-9895
2,3,7; scholarship program

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

CHADD: Children and Adults with Attention Deficit Disorders
499 NW 70th Ave, Ste 109
Plantation, FL 33317
(800) 233-4050
(305) 587-3700
(305) 587-4599 (fax)
1,2,5,6

CHADD—Canada
PO Box 23007
Ottawa, ON CAN K2A 4E2
(613) 231-7646
(613) 231-7064 (fax)
1,2,5

Autism

See also: Language Disorders

Autism Research Institute
4182 Adams Ave
San Diego, CA 92116
(619) 281-7165
1,2,3,7,10

Autism Society of America
7910 Woodmont Ave, Ste 650
Bethesda, MD 20814
(800) 328-8476
(301) 657-0881
(301) 657-0869 (fax)
1,2,4,5,6,7,8

Autism Society of Canada
129 Yorkville Ave, #202
Toronto, ON CAN M5R 1C4
(416) 922-0302
1,5,6,7,8

Center for Study of Autism
9725 SW Beaverton-Hillsdale Hwy, Ste 230
Beaverton, OR 97005
(503) 643-4121
4,5,6,7,8,9,10

More Advanced Autistic People
PO Box 524
Crown Point, IN 46307
1,2,6,8,10

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Role Models
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NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

National Autism Hotline/Autism Services Ctr
605 Ninth St
Prichard Bldg PO Box 507
Huntington, WV 25710-0507
(304) 525-8014
(304) 525-8026 (fax)
1,3,4,7

Autism & Sensory Impairments

See also: Hearing Impairments, Language Disorders, Visual Impairments

Autism and Sensory Impairments Network
c/o Dolores and Alan Bartel
7510 Oceanfront Ave
Virginia Beach, VA 23451
(804) 428-9036
4,6,7,10

Autoimmune Disorders

See also: Immune Disorders

American Autoimmune Related Diseases Association
Michigan National Bank Bldg
15475 Gratiot Ave
Detroit, MI 48205
(800) 598-4668
(313) 371-8600
(313) 371-6002 (fax)
1,2,5,7,8,9; physician seminars, public education

Balance Disorders & Dizziness

See also: Vestibular Disorders

EAR Foundation
2000 Church St, Box 111
Nashville, TN 37236
(800) 545-4327 (V/TTY)
(615) 329-7807
1,2

Pen Pal Support Group for Chronic Dizziness & Balance Disorders
307 Second St
Elliott, IA 51532
(712) 767-2325
1,4,7

Batten Disease

See also: Brain Diseases, Tay-Sachs Disease

Batten's Disease Support and Research Association
2600 Parsons Ave
Columbus, OH 43207
(800) 448-4570
(614) 445-4161
1,3,4,5,6,7,9,10

BBB Syndrome

See: Opitz Syndrome

Beckwith-Wiedemann Syndrome

Beckwith-Wiedemann Support Network
3206 Braeburn Cir
Ann Arbor, MI 48108
(800) 837-2976 (Parents only)
(313) 973-0263
(313) 973-9721 (fax)
1,2,4,6,7,10

Bedwetting

See: Incontinence

Bereavement Support

Center for Loss in Multiple Birth
PO Box 1064
Palmer, AK 99645-1064
(907) 746-6123
1,4,7

Compassionate Friends
PO Box 3696
Oak Brook, IL 60522-3696
(708) 990-0010
(708) 990-0246 (fax)
1,2,3,5,6,7

Pen-Parents
PO Box 8738
Reno, NV 89507-8738
(702) 826-7332
1,2,4,6,7

Biliary Atresia

See: Liver Disorders

Biotinidase Deficiency

See: Neurometabolic Disorders

Birthmark

See: Nevi, Giant Congenital; Vascular Malformations

Bleeding Disorders

See: Hemophilia

Blepharophimosis

Blepharophimosis, Ptosis, Epicanthus Inversus Support Group
c/o Lynne Schauble
SE 820 Meadow Vale Dr
Pullman, WA 99163
(509) 332-6628
1,2,4,7,10

Blindness

See: Visual Impairments

Bloch-Siemens-Sutzberger Syndrome

See: Incontinentia Pigmenti

Blood Vessel Malformation

See: Hemorrhagic Telangiectasis, Hereditary; Vascular Malformations

Bloom Syndrome

See: Growth Disorders

Brachmann-de Lange Syndrome

See: Cornelia de Lange Syndrome

Brain Diseases

Children's Brain Diseases Foundation
350 Parnassus Ave, Ste 900
San Francisco, CA 94117
(415) 565-6259
(415) 863-3452 (fax)
6,7,9

Brain Injury

International Brain Injury Association
1776 Massachusetts Ave NW, Ste 100
Washington, DC 20036-1904
(202) 296-6443
(202) 296-8850 (fax)
2,3,5,7,8

Brain Stem Malformations

See: Arnold-Chiari Malformation, Joubert Syndrome, Syringomyelia

Brain Tumors

See also: Brain Injury, Cancer, Epilepsy, Turcot Syndrome, Von Hippel-Lindau Syndrome

American Brain Tumor Association
2720 River Rd, Ste 146
Des Plaines, IL 60018
(800) 886-2282
(708) 827-9910
(708) 827-9918 (fax)
1,2,4,6,9

Brain Tumor Foundation of Canada
111 Waterloo St, Ste 600
London, ON CAN N6B 2M4
(519) 642-7755
(519) 642-7192 (fax)
1,2,4,6,7,8,9,10; quarterly "fun" days for children and families

Brain Tumor Society
60 Birmingham Pkwy
Boston, MA 02135-1116
(617) 783-0340
(617) 783-9712 (fax)
1,2,4,6,8,9,10

Children's Brain Tumor Foundation
35 Alpine Ln
Chappaqua, NY 10514
(914) 238-1656
(914) 238-6024 (fax)
1,2,7,8,9

National Brain Tumor Foundation
c/o Michael McKechnie
785 Market St, Ste 1600
San Francisco, CA 94102
(800) 934-2873
(415) 284-0208
(415) 284-0209 (fax)
sstf39b@prodigy.com
1,2,3,4,6,7,8,9

Burns

Phoenix Society for Burn Survivors
11 Rust Hill Rd
Levittown, PA 19056
(800) 888-2876
(215) 946-2876
(215) 946-4788 (fax)
1,2,3,4,5,6,7,8,9

Canavan Disease

See: Leukodystrophy, Tay-Sachs Disease

Cancer

See also: Brain Tumors, Leukemia, Polyposis

American Cancer Society
1599 Clifton Rd NE
Atlanta, GA 30329-4251
(800) 227-2345
1,3,4,5,6,7,8,9

Candlelighters Childhood Cancer Foundation
7910 Woodmont Ave, Ste 460
Bethesda, MD 20814
(800) 366-2223
(301) 718-2686 (fax)
12,5,6,7,8; advocacy program for insurance and second opinions

Candlelighters Childhood Cancer Foundation—Canada
10 Alcorn Ave, Ste 200
Toronto, ON CAN M4V 3B1
(416) 926-1374
(416) 961-4189 (fax)
1,2,3,4,5,6,7,8; scholarship program, financial assistance program under development

Cancer, Brain

See: Brain Tumors, Turcot Syndrome

Cancer, Colon

See: Turcot Syndrome

Cancer, Gastrointestinal

See: Peutz-Jeghers Syndrome, Polyposis

Carbamyl Phosphate Synthetase (CPS) Deficiency

See: Urea Cycle Disorders

Cardiac Disorders

See: Heart Disorders

CLOSE-UP

A Circle of Help

The International Rett Syndrome Association gives parents a shoulder to lean on

When Kathy Hunter was told, "You caused your daughter's condition," she refused to believe it. She began a 10-year search that would lead her to a Viennese doctor and an answer—Rett syndrome, a genetic disorder occurring only in females and causing mental retardation, repetitive hand gestures and a loss of purposeful hand skills.

Claudia Weisz and IRSA president Kathy Hunter oversee the IRSA booth at the World Congress on Neurology in September 1993.

Rett syndrome had not been widely recognized by professionals and is still often misdiagnosed as autism or cerebral palsy. This confusion from people she perceived as being able to fix anything often frustrated Kathy. "We needed to know what was going on," she says.

In 1983, an article in the *Annals of Neurology* brought Rett syndrome—first identified in 1966 by Dr. Andreas Rett—to the attention of the American medical community. Two years later, Stacie Hunter was diagnosed.

In the spring of 1985, Kathy founded the International Rett Syndrome Association (IRSA) with 16 other families. She wanted to make sure no other parents would be hurt by the public's lack of understanding. After 10 years of public awareness efforts, IRSA has greatly increased knowledge of the syndrome. More than $12 million has been awarded to researchers in the past decade; many feel they are within a few years of identifying the syndrome's cause and, perhaps, an effective treatment.

IRSA's major role, however, is as a support for parents. "It is a powerful, comforting force to know that you can pick up a telephone and know there's someone on the other end who knows what you're going through when your kid won't sleep nights," Kathy said. Local groups provide contacts and emotional support for families. Seminars and meetings keep parents up-to-date on the latest in research and care for a child with Rett syndrome. Benefits like a night of "Beer, Beef and Bowling" help fund the organization and provide entertainment for families. Professionals attend many of these events with parents, and often come away imbued with the passion parents feel.

Kathy Hunter is proud of the organization that started around her kitchen table. "It's liberating to know that you're not alone," she says, adding that, as president, "I don't consider it a job; I consider it a privilege."

—Jennifer M. Koerber

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

Cardio-Facio-Cutaneous Syndrome

See also: Noonan Syndrome

CFC Support Network
157 Alder Ave
McKee City, NJ 08232
(609) 646-5606
1,4,10

Carnitine Deficiency

See: Acidemia, Organic; Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD); Muscular Dystrophy

Carnitine Palmityltransferase Deficiency

See: Acidemia, Organic; Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD); Muscular Dystrophy

Cartilage-Hair Hypoplasia

See: Growth Disorders, Schwachman Syndrome

Caudal Syndrome

See: Growth Disorders

25

Celiac Disease

See also: Celiac Sprue, Gluten Intolerance

Celiac Disease Foundation
13251 Ventura Blvd, #3
Studio City, CA 91604-0265
(818) 990-2354
(818) 990-2379 (fax)
1,2,4,5,7,8,10

Celiac Sprue

See also: Celiac Disease, Gluten Intolerance

American Celiac Society
58 Musano Ct
West Orange, NJ 07052
(201) 325-8837
bentleac@umdnj.edu
1,4,5,6,7,8,9

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Celiac Sprue Association
PO Box 31700
Omaha, NE 68131-0700
(402) 558-0600
(402) 558-1347 (fax)
1,2,3,4,5,6,7,9

Central Core Disease
See: Muscular Dystrophy

Central Hypoventilation Syndrome, Congenital
See also: Intestinal Pseudo-Obstruction Syndrome, Ventilator Use

Congenital Central Hypoventilation Syndrome Parent Network
71 Maple St
Oneonta, NY 13820
1,4,6,10

Centronuclear Myopathy
See: Myotubular Myopathy

Cerebellar Vermis Aplasia/Hypoplasia
See: Joubert Syndrome

Cerebral Palsy

United Cerebral Palsy Associations
1522 K St NW, #1112
Washington, DC 20005
(800) 872-5827
(202) 842-1266 (V/TTY)
(202) 842-3519 (fax)
ucpainc@aol.com
1,2,3,5,6,7,8,9; therapy programs; information about technology, recreation, early intervention and employment

Cerebrotendinous Xanthomatosis
See: Leukodystrophy, Tay-Sachs Disease

Chanarin-Dorfman Syndrome
See: Ichthyosis

Charcot-Marie-Tooth Disease
See also: Ataxia, Muscular Dystrophy, Myelin Disorders

Charcot-Marie-Tooth Association
601 Upland Ave
Upland, PA 19015
(800) 606-2682
(215) 499-7486
(215) 499-7429 (fax)
1,2,3,5,7,9,10; regional conferences, physician's handbook

Charcot-Marie-Tooth International
1 Springbank Dr
St Catharines, ON CAN L2S 2K1
(905) 687-3630
(905) 687-8753 (fax)
1,2,4,7,10

CHARGE Syndrome

CHARGE Syndrome Foundation
2004 Parkade Blvd
Columbia, MO 65202-3121
(800) 442-7604
mnorbury@bigcat.missouri.edu
1,2,4,6,7,10

Chiari Malformation
See: Arnold-Chiari Malformation

CHILD Syndrome
See: Ichthyosis

Cholesteryl Ester Storage Disease
See: Tay-Sachs Disease

Chondrodysplasia Punctata
See: Growth Disorders, Ichthyosis

Choroideremia
See: Macular Diseases, Retinitis Pigmentosa, Visual Impairments

Chromosome 4p–
See: Wolf-Hirschhorn Syndrome

Chromosome 5p–
See: Cri Du Chat Syndrome

Chromosome 6 Disorders

Spotlight 6
c/o Valerie Wiggins
56 Edmundson Ln
Rising Sun, MD 21911
1,4,10

Chromosome 9 Disorders

Support Group for 9p-
c/o Beverly Udell
675 N Round Table Dr
Las Vegas, NV 89110
(702) 453-0788
1,2,3,4,7,10

Support Group for Monosomy 9p
43304 Kipton Nickle Plate Rd
La Grange, OH 44050
(216) 775-4255
1,4,10; bibliography, Japanese and French translations

Trisomy 9 International Parent Support
Children's Hospital of Michigan
3901 Beaubien Blvd
Detroit, MI 48201-2196
(313) 745-4513
(313) 745-4827 (fax)
1,4,7,10

Chromosome 15 Disorders

IDEA: Inverted Duplication Exchange & Advocacy
c/o Donna Bennett
RD #1, Box 260B
Thomasville, PA 17364-9768
(717) 225-5229
(610) 891-2313
1,4,10

Chromosome 17p–
See: Smith-Magenis Syndrome

Chromosome 18 & 13 Disorders

Chromosome 18 Registry & Research Society
6302 Fox Head
San Antonio, TX 78247
(210) 657 4968 (voice/fax)
1,4,6,10

SOFT: Support Organization for Trisomy 18, 13 and Related Disorders
c/o Barb Van Herreweghe
2982 S Union St
Rochester, NY 14624
(716) 594-4621 (voice/fax)
1,2,4,5,6,7,10

SOFT—Canada: Support Organization for Trisomy 18, 13 and Related Disorders
760 Brant St, Ste 420
Burlington, ON CAN L7R 4B8
(800) 668-0898 (Canada only)
(905) 632-7755
(905) 632-5997 (fax)
1,2,4,6,10

Chromosome 22 Disorders
See: DiGeorge Syndrome, Velo-Cardio-Facial Syndrome

Chromosome 45,X0
See: Turner Syndrome

Chromosome 45,X0/46,XX
See: Turner Syndrome

Chromosome 47,XXY
See: Klinefelter Syndrome

Chromosome 48,XXXY
See: Klinefelter Syndrome

Chromosome 49,XXXXY
See: Klinefelter Syndrome

Chromosome Deletions

Chromosome Deletion Outreach
Box 280
Driggs, ID 83422
(208) 354-8550
1,4,7,10; also deals with chromosome additions, inversions and translocations

Chromosome Inversions

National Center on Chromosome Inversions
1029 Johnson St
Des Moines, IA 50315
(515) 287-6798 (voice/fax)
4,7,8,10

Citrullinemia
See: Urea Cycle Disorders

Cleft Palate
See also: Craniofacial Disorders

Cleft Palate Foundation
1218 Grandview Ave
Pittsburgh, PA 15211
(800) 242-5338
(412) 481-1376
(412) 481-0847 (fax)
2,4,6,7,9

Cockayne Syndrome
See also: Growth Disorders, Progeria, Xeroderma Pigmentosum

Share and Care Cockayne Syndrome Network
c/o Theresa Wall
PO Box 552
Stanleytown, VA 24168
(703) 629-2369
(703) 647-3739 (fax)
1,2,10

Coffin-Lowry Syndrome

Coffin-Lowry Syndrome Foundation
PO Box 10003
Bainbridge Island, WA 98110
(206) 842-1523
1,2,4,10

Coffin-Sirius Syndrome
See: Coffin-Lowry Syndrome

Colitis
See: Crohn's Disease & Colitis

Coloboma
See: Visual Impairments

Conradi-Hünermann Syndrome
See: Growth Disorders, Ichthyosis

Cooley's Anemia

Cooley's Anemia Foundation
12909 26th Ave
Flushing, NY 11354
(800) 552-7222
(718) 321-2873
(718) 321-3340 (fax)
1,2,3,4,5,6,7,8,9,10; financial assistance, fellowships

Cornelia de Lange Syndrome

Cornelia de Lange Syndrome Foundation
60 Dyer Ave
Collinsville, CT 06022-1273
(800) 223-8355
(800) 753-2357
(203) 693-0159
(203) 693-6819 (fax)
1,2,3,4,6,10; professional network

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Corpus Callosum, Disorders of

See: Agenesis of the Corpus Callosum

Craniocarpotarsal Dystrophy

See: Freeman-Sheldon Syndrome

Craniofacial Disorders

See also: Apert Syndrome, Cleft Palate, Crouzon's Disease, Freeman-Sheldon Syndrome, Goldenhar Syndrome, Holoprosencephaly, Microtia, Moebius Syndrome, Nager & Miller Syndromes, Treacher Collins Syndrome

AboutFace–Canada
99 Crowns Ln, 3rd Floor
Toronto, ON CAN M5R 3P4
(800) 665-3223
(416) 944-3223
(416) 944-2488 (fax)
1,2,3,4,5,6,7; program to teach school children about facial differences, outreach program to families with newborns

AboutFace–USA
PO Box 737
Warrington, PA 18976
(800) 225-3223
(215) 491-0603 (fax)
AbtFace@aol.com
1,2,3,4,5,6,7,8; program to teach school children about facial differences

Children's Craniofacial Association
10210 N Central Expressway
Ste 230, LB37
Dallas, TX 75231
(800) 535-3643
(214) 994-9902
(214) 994-9831 (fax)
1,2,4,6,7,10

Craniofacial Foundation of America
c/o Terri Farmer
975 E Third St
Chattanooga, TN 37403
(615) 778-9192
1,2,4,5,7,10; financial assistance for non-medical expenses

FACES–National Association for the Craniofacially Handicapped
PO Box 11082
Chattanooga, TN 37401
(800) 332-2373
(615) 267-3124 (fax)
1,4,7,8,10

Forward Face
Inst of Reconstructive Plastic Surgery
317 34th St, 9th Fl
New York, NY 10016
(800) 422-3223
(212) 263-5205
(212) 263-7534 (fax)
1,3,4,7; apartment in NYC for families of children undergoing treatment, adolescent support group, assistance with transportation costs, scholarships

Let's Face It
PO Box 711
Concord, MA 01742
(508) 371-3186
1,4,7,8; annual resource guide

National Foundation for Facial Reconstruction
317 E 34th St, Rm 901
New York, NY 10016
(800) 422-3223
(212) 263-6656
(212) 263-7534 (fax)
1,4,6,7,8,9,10

Craniosynostosis

See: Craniofacial Disorders

Cri Du Chat Syndrome

5p-Society
11609 Oakmont
Overland Park, KS 66210
(913) 469-8900
1,2,4,6,7,8,9,10

Crohn's Disease & Colitis

CCFA: Crohn's & Colitis Foundation of America
386 Park Ave S, 17th Floor
New York, NY 10016-8804
(800) 932-2423
(212) 685-3440
(212) 779-4098 (fax)
1,5,7,9

Pediatric Crohn's & Colitis Association
Box 188
Newton, MA 02168
(617) 290-0902
1,2,4,7

Crouzon's Disease

See also: Craniofacial Disorders, Hearing Impairments

Crouzon's/Meniere's Parent Support Network
c/o Kathleen Handsaker
PO Box 12791
Prescott, AZ 86304-2791
(602) 445-1743
(After March 1, 1995, 602 area code changes to 520)
4,7

Cushing Syndrome

See: Adrenal Disorders; Adrenal Hyperplasia, Congenital

Cyclic Vomiting Syndrome

Cyclic Vomiting Syndrome Association
13180 Caroline Ct
Elm Grove, WI 53122
(414) 784-6842
(414) 821-5494 (fax)
Kadams@post.its.mcw.edu
1,2,3,4,5,6,7,9,10

Cystic Fibrosis

Canadian Cystic Fibrosis Foundation
2221 Yonge St, Ste 601
Toronto, ON CAN M4S 2B4
(800) 378-2233 (Canada only)
(416) 485-9149
(416) 485-0960 (fax)
1,2,3,5,6,7,8,9,10

Cystic Fibrosis Foundation
6931 Arlington Rd
Bethesda, MD 20814
(800) 344-4823
(301) 951-4422
(301) 951-6378 (fax)
1,2,3,5,6,7,8,9,10

Cystinosis

See also: Kidney Disorders

Cystinosis Foundation
1212 Broadway, Ste 830
Oakland, CA 94612
(800) 392-8458
1,4,6,7,8,9,10

Cystinuria

See also: Kidney Disorders

Cystinuria Support Network
22814 NE 21st Pl
Redmond, WA 98053
(206) 868-2996
75512.3161@compuserve.com
1,4,10

Cytomegalovirus (CMV), Congenital

National CMV Registry
c/o Gail Demmler, MD
Texas Children's Hospital
Clinical Care Center, Ste 1150
6621 Fannin St, MC 3-2371
Houston, TX 77030-2399
(713) 770-4330
(713) 770-4347 (fax)
1,4,7

Darier Disease

See: Ichthyosis

Deaf-Blind

See also: Hearing Impairments, Visual Impairments

American Association of the Deaf-Blind
814 Thayer Ave, Ste 302
Silver Spring, MD 20910
(301) 588-6545 (TTY only)
(301) 588-8705 (fax)
1,4,6,7,8

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

DB-LINK: National Information Clearinghouse on Children Who are Deaf-Blind
345 N Monmouth Ave
Monmouth, OR 97361
(800) 438-9376
(800) 854-7013 (TTY)
LeslieG@fsa.wosc.osshe.edu
1,4,7,8

National Family Association for the Deaf-Blind
111 Middle Neck Rd
Sands Point, NY 11050
(800) 255-0411 (V/TTY)
(516) 944-8900 (voice)
(516) 944-8637 (TTY)
1,4,5,7,8

Deafness

See: Hearing Impairments

Debrancher Enzyme Deficiency

See: Muscular Dystrophy

Dejerine Sottas Disease

See: Muscular Dystrophy

Dermatitis Herpetiformis

See: Celiac Disease, Celiac Sprue, Gluten Intolerance

Dermatomyositis

See: Arthritis, Muscular Dystrophy, Myositis

Diabetes Insipidus

Diabetes Insipidus and Related Disorders Network
c/o Beth Perry
Rt 2, Box 198
Creston, IA 50801
(515) 782-7838
1,4

Diabetes Mellitus

American Diabetes Association
National Service Ctr
1660 Duke St
Alexandria, VA 22314
(800) 232-3472
(703) 549-1500
(703) 683-2890 (fax)
1,2,3,5,6,7,9,10

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Canadian Diabetes Association
15 Toronto St, Ste 1001
Toronto, ON CAN M5C 2E3
(416) 363-3373
(416) 363-3393 (fax)
1,5,8,9

Juvenile Diabetes Foundation—Canada
89 Granton Dr
Richmond Hill, ON CAN L4B 2N5
(800) 668-0274 (Canada only)
(905) 889-4171
(905) 889-4209 (fax)
1,3,5,6,8,9

Juvenile Diabetes Foundation International
432 Park Ave S, 16th Fl
New York, NY 10016
(800) 533-2873
(212) 889-7575
(212) 532-8791 (fax)
jBROCH@jdf.usa.com
1,2,5,9

DiGeorge Syndrome
See also: Immune Disorders, Velo-Cardio-Facial Syndrome

Information and Support for DiGeorge and Shprintzen Syndrome Families
c/o Natalie Ward
27859 Lassen St
Castaic, CA 91384
(805) 294-3623
1,4,7,10

Digestive Disorders
See: Celiac Disease, Celiac Sprue, Crohn's Disease & Colitis, Gluten Intolerance, Ostomy

Dimorsier Syndrome
See: Growth Disorders

Down Syndrome

Association for Children with Down Syndrome
2616 Martin Ave
Bellmore, NY 11710
(516) 221-4700
(516) 221-4311 (fax)
1,2,3,7,9

Canadian Down Syndrome Society
12837 76th Ave, Ste 206
Surrey, BC CAN V3W 2V3
(604) 599-6009
(604) 599-6165 (fax)
1,2,3,4,5,6,7

International Foundation for Genetic Research
400 Penn Center Blvd, Ste 721
Pittsburgh, PA 15235
(412) 823-6380
(412) 829-7304 (fax)
1,8,9; anti-abortion advocacy

National Down Syndrome Congress
1605 Chantilly Dr, Ste 250
Atlanta, GA 30324
(800) 232-6372
(404) 633-1555
(404) 633-2917 (fax)
1,4,6,7,8,10

National Down Syndrome Society
666 Broadway, 8th Fl
New York, NY 10012-2317
(800) 221-4602
(212) 460-9330
(212) 979-2873 (fax)
1,2,3,5,6,7,8,9,10

Dubowitz Syndrome
See: Growth Disorders

Dwarfism
See also: Growth Disorders, Short Stature

Billy Barty Foundation
929 W Olive Ave, Ste C
Burbank, CA 91506
(818) 953-5410
(818) 953-7129 (fax)
1,2,3,7,8; emergency financial assistance, scholarships

Dysautonomia, Familial

Dysautonomia Foundation
20 E 46th St, Rm 302
New York, NY 10017
(212) 949-6644
(212) 682-7625 (fax)
1,2,5,6,10; treatment center

Dyslexia
See also: Attention Deficit Disorder, Language Disorders, Learning Disabilities

Dyslexia Research Institute
4745 Centerville Rd
Tallahassee, FL 32308
(904) 893-2216
(904) 893-2440 (fax)
1,2,7,8

Orton Dyslexia Society
Chester Bldg, Ste 382
8600 La Salle Rd
Baltimore, MD 21286-2044
(800) 222-3123
(410) 296-0232
(410) 321-5069 (fax)
1,2,5,6,7,9

Dyspraxia
See: Apraxia

Dystonia

Dystonia Medical Research Foundation
One E Wacker Dr, Ste 2900
Chicago, IL 60601-2001
(312) 755-0198
(312) 321-5710 (fax)
dystfdtn@aol.com
1,2,3,5,6,9; "Operation Friendship" program for young people with dystonia

Dystrophic Epidermolysis Bullosa

DEBRA: Dystrophic Epidermolysis Bullosa Research Association
40 Rector St
New York, NY 10006
(212) 693-6610
1,2,3,4,5,6,7,8,9,10

Ear Anomalies
See: Craniofacial Disorders, Microtia

Ectodermal Dysplasia

National Foundation for Ectodermal Dysplasias
219 E Main, PO Box 114
Mascoutah, IL 62258-0114
(618) 566-2020
(618) 566-4718 (fax)
1,2,3,4,5,6,7,8,9,10

Ehlers-Danlos Syndrome

Ehlers-Danlos National Foundation
PO Box 1212
Southgate, MI 48195
(313) 282-0180
(313) 282-2793 (fax)
1,2,3,4,5,6,7,9,10

Encephalitis, Chronic with Seizures
See: Rasmussen Syndrome

Epicanthus Inversus
See: Blepharophimosis

Epidermolysis Bullosa
See: Dystrophic Epidermolysis Bullosa

Epidermolytic Hyperkeratosis
See: Ichthyosis

Epilepsy
See also: Seizure Disorders

American Epilepsy Society
638 Prospect Ave
Hartford, CT 06105-4298
(203) 586-7505
(203) 586-7550 (fax)
1,2

Epilepsy Canada
1470 Peel St, Ste 745
Montreal, PQ CAN H3A 1T1
(514) 845-7855
(514) 845-7866 (fax)
1,5,7,9

Epilepsy Foundation of America
4351 Garden City Dr
Landover, MD 20785-2267
(800) 332-1000
(800) 332-2070 (TTY)
(301) 459-3700
(301) 577-4941 (fax)
1,4,5,6,7,8,9; employment services, library

Erythrokeratodermias
See: Ichthyosis

Esophageal Atresia
See: VATER Association

Essential Tremor
See: Tremor

Evans Syndrome
See also: Autoimmune Disorders

Evans Syndrome Support and Research Group
c/o Lou Addington
5630 Devon St
Port Orange, FL 32127
(904) 760-3031
(904) 760-5583 (fax)
4,5,7,10

Extracorporeal Membrane Oxygenation

ECMO Moms and Dads International Parent Support
PO Box 53848
Lubbock, TX 79453
(806) 794-0259
1,2,4,5,6,7,10

Fabry Disease
See: Tay-Sachs Disease

Facial Disfigurement
See: Craniofacial Disorders

Facio-Scapulo-Humeral Muscular Dystrophy
See also: Muscular Dystrophy

Facio-Scapulo-Humeral Society
3 Westwood Rd
Lexington, MA 02173
(617) 860-0501
1,4,5,6,7,8,9

Fanconi Anemia
See: Anemia, Fanconi

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Fetal Alcohol Syndrome/Effect

Family Empowerment Network: Support for Families Affected by FAS/FAE
610 Langdon St, Rm 521
Madison, WI 53703
(800) 462-5254
(608) 262-6590
(608) 265-2329 (fax)
1,2,4,6,7; lending library

Fetal Alcohol Education Program
7 Kent St
Brookline, MA 02146
(617) 739-1424
(617) 566-4019
2,7

Fetal Alcohol Network
158 Rosemont Ave
Coatesville, PA 19320-3727
72157.564@compuserve.com
1,4,6,7

National Organization on Fetal Alcohol Syndrome
1815 H St NW, Ste 710
Washington, DC 20006
(202) 785-4585
(202) 466-6456 (fax)
1,2,3,6,7

The Fetal Alcohol Syndrome Family Resource Institute
PO Box 2525
Lynnwood, WA 98036
(206) 778-4048
1,2,4,7,8,10; crisis-intervention line, teen prevention program for high schools

Fibrodysplasia Ossificans Progressiva

International Fibrodysplasia Ossificans Progressiva Association
910 N Jericho Dr
Casselberry, FL 32707
(407) 365-4194 (voice/fax)
1,2,3,4,6,9,10

Fibromyalgia
See: Arthritis

Fibular Hemimelia
See: Limb Disorders

Forbes Disease
See: Glycogen Storage Disease

Fragile X Syndrome
See also: Attention Deficit Disorder, Autism, Learning Disabilities

FraXa Research Foundation
PO Box 935
West Newbury, MA 01985
(508) 462-1990
fraxa@destek.net
1,2,4,5,8,9,10

National Fragile X Foundation
1441 York St, Ste 215
Denver, CO 80206
(800) 688-8765
(303) 333-6155
(303) 333-4369 (fax)
1,2,3,4,7,10

Freeman-Sheldon Syndrome
See also: Craniofacial Disorders

Freeman-Sheldon Parent Support Group
509 E Northmont Wy
Salt Lake City, UT 84103
(801) 364-7060
1,2,4,7,10

Friedreich's Ataxia
See: Muscular Dystrophy

Fucosidosis
See: Tay-Sachs Disease

G Syndrome
See: Opitz Syndrome

Galactosemia
See also: Neurometabolic Disorders

Parents of Galactosemic Children
2871 Stagecoach Dr
Valley Springs, CA 95252
(209) 772-2449 (voice/fax)
1,4,5,6,9,10

Gaucher Disease
See also: Tay-Sachs Disease

National Gaucher Foundation
11140 Rockville Pike, Ste 350
Rockville, MD 20852-3106
(800) 925-8885
(301) 816-1515
(301) 816-1516 (fax)
1,2,5,6,7,9

Giroux-Barbeau Syndrome
See: Ichthyosis

Glaucoma

Glaucoma Research Foundation
490 Post St, Ste 830
San Francisco, CA 94102
(800) 826-6693
(415) 986-3162
(415) 986-3763 (fax)
1,2,4,7,9

Glutaricaciduria II
See: Acidemia, Organic

Gluten Intolerance
See also: Celiac Disease, Celiac Sprue

Gluten Intolerance Groups of North America
PO Box 23053
Seattle, WA 98102-0353
(206) 325-6980
(206) 850-2394 (fax)
1,2,3,4,6,7,8,9,10

Glycogen Storage Disease
See also: Hypoglycemia

Association for Glycogen Storage Disease
PO Box 896
Durant, IA 52747
(319) 785-6038 (voice/fax)
1,6,9,10

Glycosphingolipidoses
See also: Tay-Sachs Disease

Goldenhar Syndrome
See also: Craniofacial Disorders

Goldenhar Syndrome Research & Information Fund
8829 Gleneagles Ln
Darien, IL 60561
(708) 910-3939
(708) 910-4065 (fax)
4,7,9,10

Granulomatous Disease, Chronic
See also: Autoimmune Disorders, Wegener Granulomatosis

Chronic Granulomatous Disease Association
c/o Mary Hurley
2616 Monterey Rd
San Marino, CA 91108
(818) 441-4118
1,4,7,9,10

Graves Disease
See also: Thyroid Disorders

National Graves Disease Foundation
320 Arlington Rd
Jacksonville, FL 32211
(904) 724-0770 (voice/fax)
1,2,3,4,5,6,7

Group B Strep

Canadian Group B Strep Association
c/o Donna Vlicny
343 Watson Ave
Windsor, ON CAN N8S 3S3
(519) 948-6324
4,7; information packets for health care professionals

Group B Strep Association
PO Box 16515
Chapel Hill, NC 27516
(919) 932-5344 (voice/fax)
1,2,4,6,7,8,10

Growth Disorders
See also: Dwarfism, Short Stature

Human Growth Foundation
7777 Leesburg Pike
Falls Church, VA 22043
(800) 451-6434
(703) 883-1773
(703) 883-1776 (fax)
1,2,3,4,5,6,7,9,10

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

Little People's Research Fund
80 Sister Pierre Dr
Towson, MD 21204
(800) 232-5773
(410) 494-0055
(410) 494-0060 (fax)
1,3,4,5,7,9,10

MAGIC Foundation for Children's Growth
1327 N Harlem Ave
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808
(708) 383-0899 (fax)
1,2,3,4,5,6,7,10

Growth Hormone Deficiency
See: Growth Disorders

Growth Retardation, Intrauterine
See: Growth Disorders

Halley-Halley Disease
See: Ichthyosis

Hallerman-Streiff Syndrome
See: Craniofacial Disorders, Short Stature

Hand-Shoulder Syndrome
See: Reflex Sympathetic Dystrophy Syndrome

Harlequin Ichthyosis
See: Ichthyosis

Head Injuries

National Head Injury Foundation
1776 Massachusetts Ave NW, Ste 100
Washington, DC 20036-1904
(800) 444-6443 (helpline)
(202) 296-6443
(202) 296-8850 (fax)
1,2,3,5,6,7,8

Hearing Impairments

Alexander Graham Bell Association for the Deaf
3417 Volta Pl NW
Washington, DC 20007-2778
(202) 337-5220 (V/TTY)
1,2,3,4,5,6,7,8,9,10

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

American Society for Deaf Children
2848 Arden Wy, Ste 210
Sacramento, CA 95825-1373
(800) 942-2732 (V/TTY)
(916) 482-0121 (fax)
1,4,5,6,7,8; "First-Year-Free" Program for families of newly diagnosed children

Auditory-Verbal International
2121 Eisenhower, Ste 402
Alexandria, VA 22314
(703) 739-1049
(703) 739-0874 (TTY)
(703) 739-0395 (fax)
1,4,6

Better Hearing Institute
PO Box 1840
Washington, DC 20013
(800) 327-9355 (V/TTY)
(703) 750-9302 (fax)
1,2,3,7

Canadian Hard of Hearing Association
2435 Holly Ln, Ste 205
Ottawa, ON CAN K1V 7P2
(800) 263-8068 (Canada only)
(613) 526-1584
(613) 526-2692 (TTY)
(613) 526-4718 (fax)
1,5,6,7,8; publications in French and English

Canadian Hearing Society
271 Spadina Rd
Toronto, ON CAN M5R 2V3
(416) 964-9595
(416) 964-0023 (TTY)
(416) 964-2066 (fax)
chs-ho@chs.onramp.ca
1,2,3,5,6,7,8

Cochlear Implant Club International
PO Box 464
Buffalo, NY 14223
(716) 838-4662 (V/TTY)
76207.3114@compuserve.com
1,4,5,6,7,8

HEAR Now
9745 E Hampden Ave, Ste 300
Denver, CO 80231-4923
(800) 648-4327 (V/TTY)
(303) 695-7797 (V/TTY)
(303) 695-7789 (fax)
1,9; financial assistance for hearing aids and cochlear implants

John Tracy Clinic
806 W Adams Blvd
Los Angeles, CA 90007
(800) 522-4582 (V/TTY)
(213) 748-5481
(213) 747-2924 (TTY)
(213) 749-1651 (fax)
1,7,8; free correspondence course for pre-schoolers

National Association of the Deaf
814 Thayer Ave
Silver Spring, MD 20910-4500
(301) 587-1788
(301) 587-1789 (TTY)
(301) 587-1791 (fax)
1,2,5,6,7,8

National Cued Speech Association
PO Box 31345
Raleigh, NC 27622
(919) 828-1218 (V/TTY)
(919) 828-1862 (fax)
ncsa@aol.com
1,2,3,4,5,6,7,8,10,11

NIDCD Hereditary Hearing Impairment Resource Registry
Boys Town National Research Hospital
55 N 30th St
Omaha, NE 68131
(800) 320-1171 (V/TTY)
(402) 498-6331 (fax)
deaf@boystown.org
1,2,7,10

Self-Help for Hard of Hearing People
7910 Woodmont Ave, Ste 1200
Bethesda, MD 20814
(301) 657-2248
(301) 657-2249 (TTY)
(301) 913-9413 (fax)
1,4,5,6,7,8

Signing Exact English (SEE) Center for the Advancement of Deaf Children
PO Box 1181
Los Alamitos, CA 90720
(310) 430-1467 (V/TTY)
(310) 795-6614 (fax)
3,7,9

Telecommunications for the Deaf, Inc
8719 Colesville Rd, Ste 300
Silver Spring, MD 20910
(301) 589-3786
(301) 589-3006 (TTY)
(301) 589-3797 (fax)
ztdias@gallua.gallaudet.edu
1,2,3,6,7,8

TRIPOD Grapevine
2901 N Keystone St
Burbank, CA 91504
(800) 352-8888 (V/TTY)
(800) 287-4763 (V/TTY, CA only)
3,4,7

VOICE for Hearing-Impaired Children
124 Eglinton Ave W, Ste 420
Toronto, ON CAN M4R 2G8
(416) 487-7719 (V/TTY)
(416) 487-7423 (fax)
1,4,5,7,8

Heart Disorders

American Heart Association
7272 Greenville Ave
Dallas, TX 75231-4596
(800) 242-8721
(214) 373-6300
(214) 369-3685 (fax)
1,2,3,7,8,9

CHASER: Congenital Heart Anomalies—Support, Education & Resources
2112 N Wilkins Rd
Swanton, OH 43558
(419) 825-5575
(419) 825-2880 (fax)
75050.2742@compuserve.com
1,4,7,8,10

Hemangioma

See also: Vascular Malformations

Hemangioma Hope
c/o Cindy Dougan
8400 Rohl Rd
North East, PA 16428
(814) 898-1054
1,2,3,4,6,10

Hemidysplasia, Unilateral

See: Ichthyosis

Hemifacial Microsomia

See: Goldenhar Syndrome

Hemihypertrophy

See: Beckwith-Wiedemann Syndrome

Hemiplegia, Alternating

See also: Epilepsy, Seizure Disorders

International Foundation for Alternating Hemiplegia of Children
29 Leonard Rd
Melrose, MA 02176
(617) 665-8906
4,9,10

Hemolytic Anemia

See: Evans Syndrome

Hemophilia

Canadian Hemophilia Society
1450 City Councillors, Ste 840
Montreal, PQ CAN H3A 2E6
(800) 668-2686 (Canada only)
(514) 848-0503, ext 24
(514) 848-9661 (fax)
1,2,3,4,5,6,7,8,9

National Hemophilia Foundation
110 Greene St, Rm 303
New York, NY 10012
(212) 219-8180
(212) 966-9247 (fax)
1,2,3,4,5,6,7,8,9,10

Hemorrhagic Telangiectasis, Hereditary

See also: Anemia, Aplastic; Vascular Malformations

HHT Foundation International
PO Box 8087
New Haven, CT 06530
(800) 448-6389 (US only)
(313) 561-2537 (US)
(313) 561-4585 (US, fax)
(604) 596-3418 (Canada)
(604) 596-0138 (Canada, fax)
1,2,4,6,10; pen-pal group

Hermansky-Pudlak Syndrome

See also: Albinism & Hypopigmentation, Visual Impairments

Hermansky-Pudlak Syndrome Network
39 Riveria Ct
Malverne, NY 11565-1602
(800) 789-9477
(516) 599-2077
2,4,8,9,10

Hers Disease

See: Glycogen Storage Disease

Hirschsprung Disease

See: Intestinal Pseudo-Obstruction Syndrome

Histiocytosis

See also: Diabetes Insipidus, Growth Disorders

Histiocytosis Association of America
609 New York Rd
Glassboro, NJ 08028
(800) 548-2758
(609) 589-6614 (fax)
1,2,4,7,9,10; financial support

Holoprosencephaly

See also: Craniofacial Disorders

Holoprosencephaly—Fighters of Defects Support Group
3032 Brereton St
Pittsburgh, PA 15219
(412) 687-6437
5,7,10

Human Immunodeficiency Virus (HIV)

See: AIDS

Hunter Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Hurler Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Hurler-Scheie Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Is This Going to be Sad?

A "Wolf-Hirschhorn family reunion" is a time to share tears and laughter

When Craig Richardson was diagnosed with Wolf-Hirschhorn syndrome, a rare chromosomal disorder also known as 4p-, his parents, Tom and Becky, were told he would not live long and would never do the same things as other children. Although the syndrome was extremely rare, Becky believed there had to be other families out there. Ten years ago, when Craig was three years old, Becky sent a *Search* letter to *Exceptional Parent*. Over the next six months, she received eight responses. Those letters marked the start of the Wolf-Hirschhorn Parent Network.

***It wasn't sad:** Enjoying an impromptu get-together at the second Wolf-Hirschhorn reunion are (from left) Stephanie Higgins, Wanda Hill, Christopher Hill, Craig Richardson (partially hidden), A.J. Grimmett, Christine Gold, Justin Furr, Kelly Gold and Brian Jungen.*

Connections and hope

Because so little was known about the syndrome, Becky's first initiative was to set up an information exchange. Parents were asked to submit a biography of their child in exchange for receiving biographies of other children.

Sometimes these histories proved medically valuable as the experiences of others alerted "newer" parents that their children were at risk of developing seizure disorders, curvature of the spine and eye disease.

The biographies also provided feelings of connection and hope. Parents discovered that other children with the syndrome also love mirrors, balloons, music and motion. They learned that some *do* learn to walk, some *can* be toilet trained and even those with the most limited skills respond to love, enjoy rough-housing and unfailingly give the gift of a smile.

The group's first "get-together," held in Iowa in 1992, was attended by 25 families—mostly mothers and children. It was such a rewarding experience, they went home to encourage their husbands and other relatives to attend the next "Reunion."

Is this going to be sad?

But Christopher's father wasn't sure he really wanted to spend time with other families affected by his son's syndrome. "Is this going to be sad?" he asked upon arrival at the group's second Reunion.

Sara Wood, one of the event organizers, flung open the door to her family's hotel room. Inside were various members of four families—children with the syndrome, parents, siblings and a grandmother. The sounds of laughing, non-stop talking and children playing could be heard. Scattered about were suitcases, wheelchairs, photo albums and toys. "Does *this* look sad?" Sara asked.

The event, held in Asheville, North Carolina, drew families from as far away as California, Canada and Germany. Michelle, 23, was the oldest person with the syndrome at the reunion—she had been diagnosed only in the past year. Anthony, the youngest child, was 21 months old. Also attending were one foster family, two adoptive families and one family whose infant with the syndrome had died.

What a support to be with others...

The event gave families a chance to ask questions and share experiences. One mother probably summed up the experiences of many—"After I was here a little while, I just started crying... I can't tell you how happy I am that I came—just to see the other children, to see their ages, to meet their families. They feel like friends I have known all my life... What a support to be with others who also appreciate and love their children!"

And Christopher's father? He left the reunion with a smile on his face and said, "It *wasn't* sad."

—Christine N. Kleimola

Christine Kleimola is the adoptive mother of Rachael Melinda, 5. Christine and Rachael live in Ypsilanti, Michigan.

Hydrocephalus

Guardians of Hydrocephalus Research Foundation
2618 Ave Z
Brooklyn, NY 11235
(718) 743-4473
(718) 743-1171 (fax)
(800) 458-8655
1,3,4,7,9

Hydrocephalus Association
870 Market St, Ste 955
San Francisco, CA 94102
(415) 776-4713
1,2,4,6,7

Hydrocephalus Support Group
PO Box 4236
Chesterfield, MO 63006-4236
(314) 532-8228
1,2,3,4,6,7

National Hydrocephalus Foundation
22427 S River Rd
Joliet, IL 60436
(815) 467-6548
1,2,3,4,5,7,10

Hyperlexia

See also: Attention Deficit Disorder, Autism, Language Disorders

The American Hyperlexia Association
479 Spring Rd
Elmhurst, IL 60126
(708) 530-8551
1,3,6,7

Hyperoxaluria

See: Oxalosis & Hyperoxaluria

Hyperthyroid Myopathy

See: Muscular Dystrophy

Hypogammaglobulinemia

See: Immune Disorders

Hypoglycemia

See also: Diabetes Mellitus

National Hypoglycemia Association
PO Box 120
Ridgewood, NJ 07451
(201) 670-1189
1,2,4,7,10

Hypopigmentation

See: Albinism & Hypopigmentation

Hypothyroid Myopathy

See: Muscular Dystrophy

Hypothyroidism, Congenital

See: Growth Disorders

Hypotonia, Benign Congenital

See: Spinal Muscular Atrophy

I-Cell Disease

See: Mucopolysaccharidosis, Tay-Sachs Disease

Ichthyosis

FIRST: Foundation for Ichthyosis and Related Skin Types
PO Box 20921
Raleigh, NC 27619
(800) 545-3286
(919) 782-5728
(919) 781-0679 (fax)
1,2,4,5,6,7,8,10

Illiostomy

See: Ostomy

Illness, Terminal

See also: Bereavement Support

Children's Hospice International
700 Princess St, Lower Level
Alexandria, VA 22314
(800) 242-4453
(703) 684-0330
(703) 684-0226 (fax)
1,2,3,4,6,7,8

Immune Deficiency

See: Immune Disorders

Immune Disorders

See also: Autoimmune Disorders

Immune Deficiency Foundation
25 W Chesapeake Ave, Ste 206
Towson, MD 21204
(800) 296-4433
(410) 321-6647
(410) 321-9165 (fax)
1,4,5,6,7,8,9,10

Imperforate Anus

See: Anorectal Malformations

Incontinence

Help for Incontinent People
PO Box 544
Union, SC 29379
(800) 252-3337
(803) 579-7900
(803) 579-7902 (fax)
1,7,8,10

Simon Foundation for Continence
PO Box 815
Wilmette, IL 60091
(800) 237-4666
(708) 864-3913
(708) 864-9758 (fax)
1,4,6,7,8,9

Incontinentia Pigmenti

IP Support Network
c/o Colleen Kidder
34929 Elm
Wayne, MI 48184
(313) 729-7912
1,4

Intestinal Pseudo-Obstruction Syndrome

American Pseudo-Obstruction and Hirschsprung's Disease Society
PO Box 772
Medford, MA 02155
(617) 395-4255
(617) 396-6868 (fax)
1,2,4,6,7,9,10

Intrauterine Growth Retardation

See: Growth Disorders

Intraventricular Hemorrhage

IVH Parents
PO Box 56-1111
Miami, FL 33256-1111
(305) 232-0381
(305) 232-9890 (fax)
72167.633@compuserve.com
1,4,7,8,10

Jeune Syndrome

See: Growth Disorders

Johanson-Blizzard Syndrome

See: Growth Disorders, Schwachman Syndrome

Joubert Syndrome

Joubert Syndrome Parents-in-Touch Network
12348 Summer Meadow Rd
Rock, MI 49880
(906) 359-4707
1,3,4,6

Kallman Syndrome

See: Growth Disorders

Keratosis Follicularis Spinulosa Decalvans

See: Ichthyosis

KID Syndrome

See: Hearing Impairments, Ichthyosis

Kidney Disorders

See also: Cystinosis, Oxalosis

American Kidney Fund
6110 Executive Blvd, Ste 1010
Rockville, MD 20852
(800) 638-8299
(301) 881-0898 (fax)
1,2,7,9; financial aid for treatment-related expenses

Kidney Foundation of Canada
5160 Blvd Decarie, Bureau 780
Montreal, PQ CAN H3X 2H9
(514) 369-4806
(514) 369-2472 (fax)
2,3,4,5,6,7,9

National Kidney Foundation
30 E 33rd St, 11th Fl
New York, NY 10016
(800) 622-9010
(212) 889-2210
(212) 689-9261 (fax)
1,2,3,5,6,7,8,9; publications for pediatric kidney patients

Polycystic Kidney Research Foundation
922 Walnut St, Ste 411
Kansas City, MO 64106
(800) 753-2873
(816) 421-1869
(816) 421-7208 (fax)
1,2,3,5,6,8,9,10

Klvlin Syndrome

See: Growth Disorders

Klinefelter Syndrome

49, XXXY Syndrome Association
10001 NE 74th St
Vancouver, WA 98662-3801
(206) 892-7547
1,4,10

Klinefelter Syndrome and Associates
PO Box 119
Roseville, CA 95661-0119
1,4,6,10

Klinefelter's Syndrome Association of America
PO Box 93
Pine River, WI 54965
1,2,4,5,10

SEEKS: Support and Educational Exchange for Klinefelter Syndrome
1417 25th Ave Dr W
Bradenton, FL 34205-6449
(813) 750-8044
1,4,10

Klippel-Trenaunay Syndrome

See also: Nevi, Giant Congenital, Sturge-Weber Syndrome, Vascular Malformations

Klippel-Trenaunay Support Group
c/o Judy Vessey
4610 Wooddale Ave
Edina, MN 55424
(612) 925-2596
(612) 333-8685 (fax)
vesse001@staff.tc.umn.edu
1,2,6

Krabbe Disease

See: Leukodystrophy, Tay-Sachs Disease

Kugelberg-Welander Disease

See: Spinal Muscular Atrophy

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Lactate Dehydrogenase Deficiency

See: Muscular Dystrophy

Lactic-Acidosis

See also: Neurometabolic Disorders

Lactic-Acidosis Support Group
PO Box 480282
Denver, CO 80248-0282
(303) 287-4953
1,4,5,7,10

Landau-Kleffner Syndrome

See also: Autism, Epilepsy, Language Disorders

CANDLE Support Group
4414 McCampbell Dr
Montgomery, AL 36106
(205) 271-3947 (voice/fax)
1,4,5,7,8,10

Landouzy-Dejerine Dystrophy

See: Facio-Scapulo-Humeral Muscular Dystrophy

Langerhans Cell Histiocytosis

See: Histiocytosis

Language Disorders

See also: Aphasia, Acquired; Apraxia; Autism; Hyperlexia; Stuttering

TALK: Taking Action Against Language Disorders for Kids
22980 Donna Ln
Bend, OR 97701
(503) 389-0004
1,2,4,5,7,10; sibling support

Laurence-Moon-Bardet-Biedl Syndrome

See also: Kidney Disorders, Retinitis Pigmentosa

Laurence-Moon-Bardet-Biedl Syndrome Network
18 Strawberry Hill
Windsor, CT 06095
(203) 688-7880
1,4

Learning Disabilities

See also: Attention Deficit Disorder, Dyslexia

Learning Disabilities Association of America
4156 Library Rd
Pittsburgh, PA 15234
(412) 341-1515
(412) 344-0224 (fax)
1,2,3,5,6,7,8

Learning Disabilities Association of Canada
323 Chapel St, Ste 200
Ottawa, ON CAN K1N 7Z2
(613) 238-5721
(613) 235-5391 (fax)
1,2,3,6,8

National Center for Learning Disabilities
381 Park Ave S, Ste 1420
New York, NY 10016
(212) 545-7510
(212) 545-9665 (fax)
1,2,3,7,8,9; educational programs

Learning Disabilities & Gifted

See also: Attention Deficit Disorder, Dyslexia, Learning Disabilities

Parents of Gifted/LD Children
2420 Eccleston St
Silver Spring, MD 20902
(301) 986-1422
1,4

Leigh's Disease

National Leigh's Disease Foundation
608 Waldron St, PO Box 2222
Corinth, MS 38834
(601) 287-8069
(601) 286-2551 (fax)
1,2,4,5,6,7,8,9,10

Leprosy

American Leprosy Missions
1 ALM Wy
Greenville, SC 29601
(800) 543-3131
(803) 271-7040
(803) 271-7062 (fax)
1,2,3,4,6,7,9

Lesch-Nyhan Disease

International Lesch-Nyhan Disease Association
11042 Ferndale St
Philadelphia, PA 19116
(215) 677-4206
1,4,10

Leukemia

Leukemia Society of America
600 Third Ave, 4th Fl
New York, NY 10016
(800) 954-4572
(212) 573-8484
(212) 856-9686 (fax)
1,2,3,5,6,7,8,9

Leukodystrophy

See also: Myelin Disorders, Tay-Sachs Disease

United Leukodystrophy Foundation
2304 Highland Dr
Sycamore, IL 60178
(800) 728-5483
(815) 895-3211
(815) 895-2432 (fax)
(815) 895-8633 (BBS, 9600 baud)
ulf@ceet.niu.edu
1,2,3,4,6,11

Limb Disorders

See also: Amputation

Cherub Association of Families and Friends of Children with Limb Disorders
936 Delaware Ave
Buffalo, NY 14209
(716) 762-9997
1,4,5,7,10; summer camp

Superkids Newsletter
60 Clyde St
Newton, MA 02160
1,2,4,10

Lissencephaly

Lissencephaly Network
716 Autumn Ridge Ln
Fort Wayne, IN 46804
(219) 432-4310
1,2,4,6,10; DNA testing, toy library

Liver Disorders

American Liver Foundation
1425 Pompton Ave
Cedar Grove, NJ 07009
(800) 223-0179
(201) 256-2550
(201) 256-3214 (fax)
1,2,3,6,7,8,9,10

Canadian Liver Foundation
1320 Yonge St, Ste 301
Toronto, ON CAN M4T 1X2
(800) 563-5483 (Canada only)
(416) 964-1953
(416) 964-0024 (fax)
1,2,3,5,6,7,8,9

Lowe Syndrome

See also: Growth Disorders, Visual Impairments

Lowe Syndrome Association
222 Lincoln St
W Lafayette, IN 47906
(317) 743-3634
1,2,4,6,9,10

Lung Diseases

American Lung Association
1740 Broadway
New York, NY 10019
(800) 586-4872
(212) 315-8700
(212) 265-5642 (fax)
5,6,8,9; programs for schools

Canadian Lung Association
1900 City Pk Dr, Ste 508
Gloucester, ON CAN K1J 1A3
(613) 747-6776
(613) 747-7430 (fax)
1,2,3,4,5,6,7,8,9

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

Lupus Erythematosus

American Lupus Society
260 Maple Ct, Ste 123
Ventura, CA 93003
(800) 331-1802 (info line)
(805) 339-0443
1,2,4,5,6,7,9,10

Lupus Foundation of America
4 Research Pl, Ste 180
Rockville, MD 20850-3226
(800) 558-0121
(800) 558-0231 (Spanish)
(301) 670-9292
(301) 670-9486 (fax)
1,5,7,8,9

SLE Foundation
149 Madison Ave, Ste 608
New York, NY 10016
(212) 685-4118
(212) 545-1843 (fax)
1,2,5,6,7,9

Lyme Disease

Lyme Disease Foundation
1 Financial Plaza, Gold Bldg, 18th Fl
Hartford, CT 06103-2610
(800) 886-5953 (info line)
(203) 525-2000
(203) 525-8425
1,2,3,6,8,9,10

Lymphohistiocytosis, Familial Erythrophagocytic

See: Histiocytosis

Lymphohistiocytosis, Malignant

See: Cancer, Histiocytosis

Macular Diseases

See also: Retinitis Pigmentosa, Stargardt Disease, Usher Syndrome, Visual Impairments

Association for Macular Diseases
210 E 64th St
New York, NY 10021
(212) 605-3719
1,7,8,9

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Macular Degeneration Foundation
PO Box 686
Palm Beach, FL 33480
(407) 820-9215
1,7,10

Male Sex Chromosome Disorders
See: Klinefelter Syndrome

Malignant Hyperthermia

Malignant Hyperthermia Association of United States
32 S Main St, PO Box 1069
Sherburne, NY 13460
(800) 986-4287
(607) 674-7901
(800) 674-7910 (fax)
1,2,3,10

North American Malignant Hyperthermia Registry
Dept of Anesthesia, Penn State Univ
PO Box 850
Hershey, PA 17033
(717) 531-6936
(717) 531-6221 (fax)
9,10; can provide detailed individual reports to physicians

Mannosidosis
See: Tay-Sachs Disease

Maple Syrup Urine Disease
See also: Acidemia, Organic; Neurometabolic Disorders

Maple Syrup Urine Disease Family Support Group
24806 State Rd 119
Goshen, IN 46526
(219) 862-2992
(219) 862-2012 (fax)
1,2,4,6,7

Marfan Syndrome

Canadian Marfan Association
Central Plaza Postal Outlet
128 Queen St S, PO Box 42257
Mississauga, ON CAN L5M 4Z0
(905) 826-3223
(905) 826-2125 (fax)
1,3,4,5,6,10

National Marfan Foundation
382 Main St
Port Washington, NY 11050
(800) 862-7326
(516) 883-8712 (voice/fax)
1,2,3,4,5,6,8,9,10

Maroteaux-Lamy Syndrome
See: Mucopolysaccharidosis, Tay-Sachs Disease

McArdle Disease
See: Glycogen Storage Disease

McCune-Albright Syndrome
See also: Growth Disorders

McCune-Albright Syndrome Division of the MAGIC Foundation
3167 Greensburg Rd
N Canton, OH 44720
(216) 896-4455
1,4,6,10

Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)
See also: Neurometabolic Disorders

Support Group for MCAD
805 Montrose Dr
Greensboro, NC 27410
(910) 547-8682
1,4,10

Medulloblastoma, Hereditary
See: Brain Tumors, Turcot Syndrome

MELAS Syndrome
See: Growth Disorders

Melnick Needles Syndrome
See: Growth Disorders

Menke's Disease

Corporation for Menke's Disease
5720 Buckfield Ct
Fort Wayne, IN 46804
(219) 436-0137
1,2,3,4,6,7,10; physician network

Mental Illness
See also: Mental Retardation/ Mental Illness

Federation of Families for Children's Mental Health
1021 Prince St
Alexandria, VA 22314-2971
(703) 684-7710
(703) 684-5968 (fax)
paulcazzolla@mmp.org
1,2,4,5,7,8,10

National Mental Health Association
1021 Prince St
Alexandria, VA 22314-2971
(800) 969-6642 (info line)
(703) 684-7722
(703) 684-5968 (fax)
1,2,4,5,6,7,8; public-education

Mental Retardation

The Arc
500 E Border St, Ste 300
PO Box 1047
Arlington, TX 76010
(800) 433-5255
(817) 261-6003
(817) 277-0553 (TTY)
(817) 277-3491 (fax)
thearc@metro.com
1,2,3,5,6,7,8,9

Canadian Association for Community Living
4700 Keele St
Kinsman Bldg, York University
North York, ON CAN M3J 1P3
(416) 661-9611 (voice)
(416) 661-2023 (TTY)
(416) 661-5701 (fax)
1,2,5,6,7,8,9; lending library for videotapes and other materials

Voice of the Retarded
5005 Newport Dr, Ste 108
Rolling Meadows, IL 60008
(708) 253-6020
1,3,5,7,8; free legal consulting

Mental Retardation/ Mental Illness
See also: Mental Illness

National Association of the Dually Diagnosed (NADD)
110 Prince St
Kingston, NY 12401
(800) 331-5362
(914) 331-4336
(914) 331-4569 (fax)
1,3,4,5,6,7

Metabolic Disorders
See: Neurometabolic Disorders

Microphthalmia
See: Visual Impairments

Microsomia, Hemifacial
See: Craniofacial Disorders, Goldenhar Syndrome

Microtia
See also: Craniofacial Disorders

Microtia-Atresia Support Group
c/o Jack Gross
330 7th Ave, #1203
New York, NY 10001
(212) 947-0770
4,7,10

Miller Syndrome
See: Nager & Miller Syndromes

Miller-Dieker Syndrome
See: Lissencephaly

Mitochondrial Disorders

EASE: Education and Support Exchange
PO Box 1151
Monroeville, PA 15146-1151
1,4,10

Mitochondrial Disorders

Mitochondrial Disorders Foundation of America
5100-1B Clayton Rd, Ste 187
Concord, CA 94521
(510) 798-8798
(510) 682-1477 (fax)
1,4,7,8,9,10

Mitochondrial Myopathy
See: Mitochondrial Disorders, Muscular Dystrophy

Moebius Syndrome
See also: Craniofacial Disorders

Moebius Syndrome Support Group
39521 Rowen Ct
Palmdale, CA 93551
(805) 267-2570
(310) 470-2000
(914) 834-6008
1,4,6,9,10

Morquio Syndrome
See: Mucopolysaccharidosis, Tay-Sachs Disease

Motor-Sensory Neuropathy, Hereditary
See: Charcot-Marie-Tooth Disease

Moyamoya Disease
See also: Vascular Malformations

Families with Moyamoya Network
c/o Dawn Gruettner
4900 McGowan St SE
Cedar Rapids, IA 52403
(800) 261-6692
1,4,10

Mucolipidoses
See: Mucolipidosis Type IV, Mucopolysaccharidosis, Tay-Sachs Disease

Mucolipidosis Type IV
See also: Mucopolysaccharidosis, Tay-Sachs Disease

ML4 Foundation
6 Concord Dr
Monsey, NY 10952
(914) 425-0639
(914) 425-4205 (fax)
4,7,9,10

Mucopolysaccharidosis
See also: Tay-Sachs Disease

National Mucopolysaccharidosis Society
17 Kraemer St
Hicksville, NY 11801
(516) 931-6338
1,2,3,4,5,6,7,8,9,10

MPS: The Ties That Bind

The National MPS Society offers an extended family of love and support

Family is your greatest strength. Marie Capobianco first discovered this when her children, Michael and Danielle, were diagnosed with Sanfillippo-B syndrome, one of seven mucopolysaccharidosis (MPS) disorders. She discovered it again as president of the National MPS Society.

MPS and ML (mucolipidosis) disorders are progressive, enzyme-deficiency conditions, in which the cells of the body cannot produce the enzyme which breaks down sugars or fats in the cell. These products build up, causing pressure on and damaging other cells, including nerve cells. This can lead to mental retardation, limited mobility, extreme hyperactivity and drastically shortened life spans. Few children with MPS and ML survive their teen years. The National MPS Society was created to support families living with these difficult conditions.

When 10 pairs of anxious parents first met in a conference room at Johns Hopkins Hospital in February of 1974, they were determined to see something done for their children. One year later, led by Capobianco, a solid network of parents had been established.

Through phone calls, letters and local and national meetings, parents are able to share everything from the latest research information, to anecdotes of life with an "MPS kid," to the pain of losing that child only a short time later. This is the true work of the MPS Society—the continuing support of parents worn thin by children difficult to care for and taken away too soon. At the group's 20th anniversary celebration in Kissimmee, Florida in December 1994, Joni Carso, the mother of a child with MPS I, explained how it felt to spend time with similar families—"You can sit down to dinner and when [your child] starts screeching, no one will stare at you and say, 'Oh, no.'"

It is this sense of belonging to an understanding family that keeps parents involved in the organization even after their children die. Many feel even stronger ties to the group, bound by memories and by friends who continue to lend support. In a letter published in a recent edition of the society's newsletter, Susan Teer, who recently lost her daughter Sarah, captured part of this connection between MPS parents—"We know that these are not easy times for any of us... If we can get another family through a moment, we will be here to listen and to share their happiness or sadness... Our hearts reach out to all of you."

Like Susan, Marie Capobianco continues to feel a strong bond to the society, even though both Michael and Danielle passed away recently. And like so many others, she plans to stay involved in the continuing work of the group. As Marie and her family learned to live with Sanfillippo-B syndrome, her involvement with the MPS Society gave her comfort while allowing her to comfort others. "I wanted to show [other parents] that you could feel guilt and pain and love and hate towards your child and not be ashamed," she said. Over the years, Marie and the other parents involved with the MPS society have helped each other realize that the myriad emotions evoked by the experience of parenting a child with a terminal illness are legitimate and human. In doing so they have helped each other cope.

—Jennifer M. Koerber

[Above] Marie Capobianco (right), MPS president spends some time with the Kahn family at the group's 20th annual conference in Kissimmee, Florida. [Left] A wall of faces—pictures of members' children—was a focus point at the conference.

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Multiple Sclerosis

National Multiple Sclerosis Society
733 3rd Ave, 6th Fl
New York, NY 10017
(800) 344-4867
(212) 986-3240
(212) 986-7981 (fax)
1,2,3,6,7,8,9

Multiple Sulfatase Deficiency

See: Hearing Impairments, Ichthyosis, Leukodystrophy, Tay-Sachs Disease

Muscular Atrophy, Peroneal

See: Charcot-Marie-Tooth Disease

Muscular Dystrophy

See also: Facio-Scapulo-Humeral Muscular Dystrophy, Ventilator Use

Muscular Dystrophy Association
3300 E Sunrise Dr
Tuscon, AZ 85718-3208
(800) 572-1717
(602) 529-2000
(602) 529-5300 (fax)
(After March 1, 1995, 602 area code changes to 520)
74431.2513@compuserve.com
1,2,4,5,7,9; outpatient clinics, financial assistance, genetic counseling, summer camps

Muscular Dystrophy Association of Canada
150 Eglinton Ave E, Ste 400
Toronto, ON CAN M4P 1E8
(800) 567-2873 (Canada only)
(416) 488-0030
(416) 488-7523
1,2,4,5,6,7,8,9; provides equipment to families

Myasthenia Gravis

See: Muscular Dystrophy

Myelin Disorders

The Myelin Project
1747 Pennsylvania Ave NW
Ste 950
Washington, DC 20006
(202) 452-8994
(202) 785-9578 (fax)
1,9,10

The Myelin Project of Canada
c/o Julie and Wayne Simmons
4330 Spinningdale Crt
Mississauga, ON CAN L5M 3J8
(905) 567-8843
(905) 567-9189 (fax)
1,3,4,6,7,8,9,10

Myelin, Insufficient

Myelin Messenger Newsletter
c/o Ruth Anderson
HC-29, Box 686
Stable Ln
Prescott, AZ 86301-7435
(602) 776-7556
(After March 1, 1995, 602 area code changes to 520)
1

Myelodysplasia

See: Anemia, Aplastic

Myoclonus

See also: Opsoclonus-Myoclonus Syndrome

Myoclonus Families United
1564 E 34th St
Brooklyn, NY 11234
(718) 252-2133
4,7,8

Myodenylate Deaminase Deficiency

See: Muscular Dystrophy

Myositis

See also: Autoimmune Disorders

National Support Group for Myositis
PO Box 890
Cooperstown, NY 13326
(800) 230-0441
(607) 547-5216
1,4,10

Myositis Ossificans Progressiva

See: Fibrodysplasis Ossificans Progressiva

Myotonia Congenita

See: Muscular Dystrophy

Myotubular Myopathy

See also: Muscular Dystrophy

X-Linked Myotubular Myopathy Resource Group
2413 Quaker Dr
Texas City, TX 77590
(409) 945-8569
1,4,10

Myxedema

See: Thyroid Disorders

N-Acetyl Glutamate Synthetase (NAGS) Deficiency

See: Urea Cycle Disorders

Nager & Miller Syndromes

See also: Craniofacial Disorders, Limb Disorders

Foundation for Nager and Miller Syndromes (FNMS)
333 Country Ln
Glenview, IL 60025-5104
(800) 507-3667
(708) 724-6449 (voice/fax)
1,4,7,8,9,10; lending library, camp scholarships

Nasal Encephalocele

See: Craniofacial Disorders

Nemaline Myopathy

See: Muscular Dystrophy

Neonatal Illness/ Prematurity

Parent Care
9041 Colgate St
Indianapolis, IN 46268-1210
(317) 872-9913
(317) 872-0795 (fax)
1,2,4,6,7

Netherton Syndrome

See: Ichthyosis

Neurofibromatosis

See also: Acoustic Neuroma

National Neurofibromatosis Foundation
95 Pine St, 16th Fl
New York, NY 10005
(800) 323-7938 (V/TTY)
(212) 344-6633
(212) 747-0004 (fax)
NNFF@aol.com
1,2,4,5,7,9,10; medical conferences and symposia

Neurofibramatosis Institute
5415 Briggs Ave
La Crescenta, CA 91214
(818) 957-3508
(818) 957-4926 (fax)
73044.2707@compuserve.com
4,7,8,9

Neurofibromatosis, Inc.
8855 Annapolis, Ste 110
Lanham, MD 20706-2924
(800) 942-6825
(301) 577-8984
(410) 461-5213 (TTY)
(301) 577-0016 (fax)
1,2,3,5,7,8,9,10

Neurometabolic Disorders

See also: Acidemia, Organic; Galactosemia; Lactic-Acidosis; Maple Syrup Urine Disease; Niemann-Pick Disease; Phenylketonuria (PKU)

Association for Neurometabolic Disorders
5223 Brookfield Ln
Sylvania, OH 43560-1809
(419) 885-1497
1,4,6,10

Canadian Society for Metabolic Disease
5301 Ranger Ave
N Vancouver, BC CAN V7R 3M7
(604) 986-2508
(604) 293-7126 (fax)
1,2,3,4,5,6,7,8,9,10

Neuropathy, Hereditary Motor-Sensory

See: Charcot-Marie-Tooth Disease

Neuropathy, Peripheral

See: Charcot-Marie-Tooth Disease

Neutropenia

See: Evans Syndrome

Neutropenia with Pancreatic Insufficiency

See: Schwachman Syndrome

Nevi, Giant Congenital

See also: Hemangioma, Ichthyosis, Klippel-Trenaunay Syndrome, Sturge-Weber Syndrome, Vascular Malformations

Nevus Network
1400 S Joyce St, #1225
Arlington, VA 22202
(703) 920-2349
(405) 377-3403
syfv45b@prodigy.com
1,2,4,10

Neville Disease

See: Niemann-Pick Disease

Niemann-Pick Disease

See also: Ataxia, Neurometabolic Disorders, Tay-Sachs Disease

National Niemann-Pick Disease Foundation
22201 Riverpoint Trail
Carrollton, VA 23314
(804) 357-6774
1,4,6,7,9,10

Noonan Syndrome

See also: Cardio-Facio-Cutaneous Syndrome, Growth Disorders

Noonan Syndrome Society
c/o Susan Espinoza
128 Pine Ave
San Jose, CA 95125
(408) 723-5188
1,2,3,4,6,7,10

Oculo-Auricular-Vertebral (OAV) Syndrome

See: Goldenhar Syndrome

Obsessive-Compulsive Disorder

OC Foundation
PO Box 70
Milford, CT 06460
(203) 878-5669
1,2,3,4,5,6,7,9

Oligosaccharisdoses

See: Tay-Sachs Disease

Ollier's Disease

Ollier's Disease Self-Help Group
PO Box 52616
Shaw AFB, SC 29152-1521
1,4,7

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Opitz Syndrome

See also: Agenesis of the Corpus Callosum

International Optiz-Frias Syndrome Association
116 June Ave
Nanaimo, BC CAN V9S 4R7
(604) 754-7088
(604) 758-5504 (fax)
4,7,8,10

Opitz Family Network
PO Box 516
Grand Lake, CO 80447
(303) 627-8935
1,4,6,10

Opitz-Frias Syndrome

See: Opitz Syndrome

Oppenheim Disease

See: Spinal Muscular Atrophy

Opsoclonus-Myoclonus Syndrome

See also: Myoclonus

Opsoclonus-Myoclonus Parent-Talk Support Network
c/o Connie Quinn
725 North St
Jim Thorpe, PA 18229
(717) 325-3302
1,4

Optic Nerve Hypoplasia

See: Septo-Optic Dysplasia

Organic Acidemia

See: Acidemia, Organic

Ornithine Transcarbamylase (OTC) Deficiency

See: Urea Cycle Disorders

Osteogenesis Imperfecta

See also: Growth Disorders

Canadian Osteogenesis Imperfecta Society
128 Thornhill Crescent
Chatham, ON CAN N7L 4M3
1,4,6,7,9

Osteogenesis Imperfecta Foundation
5005 W Laurel St, Ste 210
Tampa, FL 33607
(813) 282-1161
(813) 287-8214 (fax)
1,2,3,4,5,6,7,8,9,10

Ostomy

United Ostomy Association
36 Executive Pk, Ste 120
Irvine, CA 92714-6744
(800) 826-0826
(714) 660-8624
(714) 660-9262 (fax)
1,2,3,5,6,7

Oxalosis & Hyperoxaluria

See also: Kidney Disorders

Oxalosis & Hyperoxaluria Foundation
PO Box 1632
Kent, WA 98035
(206) 631-0386
1,2,4,6,7,8,9,10

Pachygyria

See: Lissencephaly

Pallister-Killian Syndrome

Pallister-Killian Family Support Group
3700 Wyndale Ct
Ft Worth, TX 76109
(817) 927-8854
(817) 927-2073 (fax)
4,10

Pancreatic Insufficiency with Neutropenia

See: Schwachman Syndrome

Panhypopituitarism

See: Diabetes Insipidus, Growth Disorders

Papillomas

See: Respiratory Papillomatosis, Recurrent

Paralysis, Periodic

See: Muscular Dystrophy

Paramyotonia Congenita

See: Muscular Dystrophy

Pelizaeus-Merzbacher Disease

See: Leukodystrophy

Pemphigus, Familial

See: Ichthyosis

Pervasive Developmental Disorder (PDD)

See: Autism

Peutz-Jeghers Syndrome

See also: Polyposis

International Peutz-Jeghers Support Group
c/o Jill D. Brensinger
Johns Hopkins Hospital
550 N Broadway, Ste 108
Baltimore, MD 21205
(410) 614-4038
(410) 614-9544 (fax)
1,4,7,10

Phenylketonuria (PKU)

See also: Neurometabolic Disorders

Children's PKU Network
10515 Vista Sorrento Pkwy
San Diego, CA 92121
(619) 587-9421
(619) 450-5034 (fax)
1,4,7,10; scholarships

National PKU News
c/o Virginia Schuett
6869 Woodlawn Ave NE, Ste 116
Seattle, WA 98115-5469
(206) 525-8140
(206) 525-5023 (fax)
1,2

Phosphofructokinase Deficiency

See: Muscular Dystrophy

Phosphoglycerate Kinase Deficiency

See: Muscular Dystrophy

Phosphoglycerate Mutase Deficiency

See: Muscular Dystrophy

Phosphorylase Deficiency

See: Muscular Dystrophy

Pierre Robin Syndrome

See: Craniofacial Disorders, Growth Disorders

Pigment Disorders

See: Albinism & Hypopigmentation, Vitiligo

Pituitary/Hypothalamus Disorders

See: Diabetes Insipidus

Pityriasis Rubra Pilaris

See: Ichthyosis

Polymyositis

See: Muscular Dystrophy, Myositis

Polyostotic Fibrous Dysplasia

See: McCune-Albright Syndrome

Polyposis

See also: Peutz-Jeghers Syndrome

Familial Gastrointestinal Cancer Registry
Mount Sinai Hospital
600 University Ave, Ste 1157
Toronto, ON CAN M5G1X5
(416) 586-8334
(416) 586-8644 (fax)
1,2,3,4,7,8,10; genetic counseling, predictive testing

Intestinal Multiple Polyposis and Colorectal Cancer
c/o Ann Fagan
Reese's Crest, PO Box 11
Conyngham, PA 18219
(717) 788-1818
(717) 788-3712
(717) 788-4046 (fax)
4,7,10

Pompe Disease

See: Glycogen Storage Disease, Tay-Sachs Disease

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

Porphyria

American Porphyria Foundation
PO Box 22712
Houston, TX 77227
(713) 266-9617
1,2,4,7

Prader-Willi Syndrome

Prader-Willi Foundation
223 Main St
Port Washington, NY 11050
(800) 253-7993
(516) 944-3173 (fax)
1,7,8,9

Prader-Willi Syndrome Association
2510 S Brentwood Blvd, Ste 220
St. Louis, MO 63144
(800) 926-4797
1,2,3,4,5,6,7,8,9,10

Prader-Willi Syndrome International Information Forum
40 Holly Ln
Roslyn Heights, NY 11577
(800) 358-0682
(516) 484-7154 (fax)
visink@delphi.com
1,2,4,6,7,8,10

Prematurity

See: Neonatal Illness/Prematurity

Progeria

International Progeria Registry
c/o W. Ted Brown, MD, Ph.D.
NY State Inst for Basic Research in Developmental Disabilities
1050 Forest Hill Rd
Staten Island, NY 10314
(718) 494-5333
(718) 494-1026 (fax)
4,8,10

Proteus Syndrome

See: Neurofibromatosis

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Prune Belly Syndrome

Prune Belly Syndrome Network
1005 E Carver Rd
Tempe, AZ 85284
(602) 838-9006 (fax)
(After March 1, 1995, 602 area code changes to 520)
1,7,8

Pseudo-Hurler Polydystrophy

See: Mucopolysaccharidosis, Tay-Sachs Disease

Pseudoxanthoma Elasticum (PXE)

National Association for Pseudoxanthoma Elasticum
1884 Cherry St
Denver, CO 80220-1146
(303) 321-6347
1,7,10

Psoriasis

Canadian Psoriasis Foundation
1306 Wellington St, Ste 500A
Ottawa, ON CAN K1Y 3B2
(800) 265-0926 (Canada only)
(613) 728-4000
(613) 728-8913 (fax)
1,2,4,5,6,7,8,9

National Psoriasis Foundation
6600 SW 92nd, Ste 300
Portland, OR 97223
(503) 244-7404
(503) 245-0626 (fax)
1,2,3,4,7,8,9,10; correspondence network, used equipment, SSI information, help with insurance claims

Ptosis

See: Blepharophimosis

Purine Metabolic Disorders

Purine Research Society
5424 Beech Ave
Bethesda, MD 20814
(301) 530-0354
4,7,9,10

Rasmussen Syndrome

See also: Epilepsy, Seizure Disorders

Rasmussen Syndrome Support Group
c/o Al and Lynn Miller
8235 Lethbridge Rd
Millersville, MD 21108
(410) 987-5221
4,10

Reflex Sympathetic Dystrophy Syndrome

Reflex Sympathetic Dystrophy Association
116 Haddon Ave, Ste D
Haddonfield, NJ 08033
(609) 795-8845 (voice/fax)
1,4,5,6,7,9,10

Refsum Disease

See: Ichthyosis, Leukodystrophy, Tay-Sachs Disease

Renal Disorders

See: Kidney Disorders

Respiratory Papillomatosis, Recurrent

Recurrent Respiratory Papillomatosis Foundation
50 Wesleyan Dr
Hamilton, NJ 08690
(609) 890-0502
mstern@pucc.princeton.edu
1,2,3,4,5,6,7,8,10

Retinitis Pigmentosa

See also: Macular Diseases, Stargardt Disease, Usher Syndrome, Visual Impairments

Retinitis Pigmentosa International Society for Degenerative Eye Diseases
PO Box 900
Woodland Hills, CA 91365
(800) 344-4877
(818) 992-0500
(818) 992-3265 (fax)
1,2,3,5,7,8,9,10

RP Eye Research Foundation
c/o Sharon Cole
366 Adelaide St W, Ste 704
Toronto, ON CAN M5V 1R9
(800) 461-3331 (Canada only)
(416) 598-4951
(416) 598-9763 (fax)
1,2,5,7,9,10

The Foundation Fighting Blindness
1401 Mt Royal Ave, 4th Fl
Baltimore, MD
21217 21217-4245
(800) 683-5555
(800) 683-5551 (TTY)
(410) 225-9400
(410) 225-9409 (TTY)
(410) 225-3936 (fax)
1,4,5,6,7,9,10

Retinoblastoma

See also: Visual Impairments

National Retinoblastoma Parent Group
110 Allen Rd
Bow, NH 03304
(603) 224-4085
1,4,6,10

Retinopathy of Prematurity (ROP)

See also: Visual Impairments

Prevent Blindness in Premature Babies
c/o Margaret Wilson
PO Box 44792
Madison, WI 53744-4792
1,4,7,8,10

Rett Syndrome

Canadian Rett Syndrome Association
555 Fairway Rd
Kitchener, ON CAN N2C 1X4
(416) 494-1954
(519) 893-1169
1,5,6,7,9,10

International Rett Syndrome Association
9121 Piscataway Rd, Ste 2B
Clinton, MD 20735
(800) 818-7388
(301) 856-3334
(301) 856-3336 (fax)
irsa@paltech.com
1,2,3,4,5,6,7,8,9,10

Reye Syndrome

See: Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)

Ring Chromosome 18

See: Chromosome 18 & 13 Disorders

RSH Syndrome

See: Smith-Lemli-Opitz Syndrome

Rubinstein-Taybi Syndrome

Rubinstein-Taybi Parent Group
c/o Lorrie Baxter
PO Box 146
Smith Center, KS 66967
(913) 697-2984
1,2,4,6,10

Russell-Silver Syndrome

See also: Growth Disorders, Short Stature

Association for Children with Russell-Silver Syndrome
22 Hoyt St
Madison, NJ 07940
(201) 377-4531
(201) 822-2715 (fax)
mzacrss@aol.com
1,2,4,7

Sanfilippo Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Scheie Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Schwachman Syndrome

See also: Growth Disorders

Schwachman Syndrome Support Services
c/o Joan Mowery
44 Meadowlark Rd
Vernon, CT 06066
(203) 870-5454
1,4,7,10

Scleroderma

See also: Arthritis, Autoimmune Disorders

National Scleroderma Federation
Peabody Office Bldg
One Newbury St
Peabody, MA 01960
(800) 422-1113
(508) 535-6600
(508) 535-6696 (fax)
1,2,5,7,8,9

Scleroderma Research Foundation
PO Box 200
Columbus, NJ 08022
(800) 637-4005
(609) 723-7400
(609) 723-6700 (fax)
1,4,7,9,10

United Scleroderma Foundation
PO Box 399
Watsonville, CA 95077-0399
(800) 722-4673
(408) 728-2202
(408) 728-3328 (fax)
1,2,5,6,9

Scoliosis

National Scoliosis Foundation
72 Mount Auburn St
Watertown, MA 02172
(617) 926-0397
(617) 926-0398 (fax)
1,4,5,6,7,10

Seckel Syndrome

See: Growth Disorders

Seizure Disorders

See also: Epilepsy

THRESHOLD: Intractable Seizure Disorder Support Group & Newsletter
26 Stavola Rd
Middletown, NJ 07748-3728
(908) 957-0714
1

Septo-Optic Dysplasia

See also: Visual Impairments

FOCUS: For Our Children's Unique Sight
1583 Black Eagle Dr, Apt D
San Diego, CA 92126
(619) 271-8488 (voice/fax)
pilarh8826@aol.com
1,4,5,7,10

Severe Combined Immunodeficiency (SCID)

See: Immune Disorders

Sex Chromosome Disorders, Male

See: Klinefelter Syndrome

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Short Stature

See also: Dwarfism, Growth Disorders

Little People of America
PO Box 9897
Washington, DC 20016
(800) 243-9273 (info line)
(301) 589-0730
1,2,4,5,6

Shprintzen Syndrome

See: DiGeorge Syndrome, Velo-Cardio-Facial Syndrome

Sialidosis

See: Mucopolysaccharidosis, Tay-Sachs Disease

Sickle Cell Disease

Sickle Cell Disease Association of America
200 Corporate Pointe, Ste 495
Culver City, CA 90203-7633
(800) 421-8453
(310) 216-6363
(310 215-3722 (fax)
1,2,3,5,6,7,8

Triad Sickle Cell Anemia Foundation
1102 E Market St
Greensboro, NC 27420-0964
(800) 733-8297
(910) 274-1507
(910) 275-7984 (fax)
1,4,7; genetic counseling, camp

Skeletal Dysplasia

See: Dwarfism, Growth Disorders, Short Stature

Sly Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Smith-Lemli-Opitz Syndrome

Smith-Lemli-Opitz Advocacy & Exchange
222 Valley Green Dr
Aston, PA 19014
(215) 494-5287
1,4,10

Smith-Magenis Syndrome

PRISMS: Parents & Researchers Interested in Smith-Magenis Syndrome
11875 Fawn Ridge Ln
Reston, VA 22094
(703) 709-0568
acmsmith@nchgr.nih.gov
1,2,4,7,10

Sotos Syndrome

See also: Epilepsy, Growth Disorders, Learning Disabilities, Obsessive-Compulsive Disorder

Sotos Syndrome USA Support Association
2333 W El Moro
Mesa, AZ 85202
(602) 890-1722
(602) 890-2983 (fax)
(After March 1, 1995, 602 area code changes to 520)
1,2,3,4,5,6,7,8,9,10

Spastic Paraplegia, Familial

See: Ataxia

Speech Disorders

See: Aphasia, Apraxia, Autism, Language Disorders, Stuttering

Spina Bifida

See also: Arnold-Chiari Malformation, Hydrocephalus, Incontinence

Spina Bifida Association of America
4590 MacArthur Blvd NW, #250
Washington, DC 20007-4226
(800) 621-3141
(202) 944-3285
(202) 944-3295 (fax)
1,2,3,5,6,7

Spina Bifida Association of Canada
220-388 Donald St
Winnipeg, MB CAN R3B 2J4
(800) 565-9488 (Canada only)
(204) 957-1784
(204) 957-1794 (fax)
1,5,6,8,9

Spinal Cord Injuries

American National Spinal Cord Injury Hotline
2201 Argonne Dr
Baltimore, MD 21218
(800) 526-3456
(410) 366-2325 (fax)
5,7,10

American Paralysis Association
500 Morris Ave
Springfield, NJ 07081
(800) 225-0292
(201) 379-2690
(201) 912-9433 (fax)
1,7,9,10

National Spinal Cord Injury Association
545 Concord Ave, Ste 29
Cambridge, MA 02138
(800) 962-9629 (hotline only)
(617) 441-8500
(617) 441-3449 (fax)
1,2,4,5,6,7,8,9,10

Spinal Muscular Atrophy

See also: Muscular Dystrophy, Ventilator Use

Families of SMA
PO Box 1465
Highland Park, IL 60035-7465
(800) 886-1762
(708) 432-5551 (voice/fax)
1,3,4,5,6,7,8,9,10

Spondyloepiphyseal Dysplasia Congentia

See: Growth Disorders

Stargardt Disease

See also: Macular Diseases, Retinitis Pigmentosa, Visual Impairments

Stargardt International and Juvenile Macular Dystrophies
c/o Macular Degeneration Intl
2968 W Ina Rd, #106
Tucson, AZ 85741
(602) 797-2525 (voice/fax)
(After March 1, 1995, 602 area code changes to 520)
1,4,6,7,9,10

Sturge-Weber Syndrome

See also: Klippel-Trenaunay Syndrome; Nevi, Giant Congenital; Vascular Malformations

Sturge-Weber Foundation
PO Box 418
Mt Freedom, NJ 07970
(800) 627-5482
(201) 895-4445
(201) 895-4846 (fax)
1,2,3,4,6,7,8,10

Sturge-Weber Foundation—Canada
1960 Prairie Ave
Port Coquitlam, BC CAN V3B 1V4
(604) 942-9209
(604) 942-6429 (fax)
4,5,7,10

Stuttering

National Center for Stuttering
200 E 33rd St
New York, NY 10016
(800) 221-2483
(212) 532-4445 (fax)
7,10

National Stuttering Project
2151 Irving St, Ste 208
San Francisco, CA 94122-1609
(800) 364-1677
(415) 566-5324
(415) 664-3721 (fax)
1,5,6,7,8,10

Speak Easy
c/o Mike Hughes
95 Evergreen Ave
St John, NB CAN E2N 1H4
(506) 696-6799
(506) 657-1224 (fax)
1,5,7,8

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

Stuttering Foundation of America
PO Box 11749
Memphis, TN 38111-0749
(800) 992-9392
(901) 452-7343
(901) 452-3931 (fax)
stuttersfa@aol.com
1,2,3,6,7,8

Stuttering Resource Foundation
123 Oxford Rd
New Rochelle, NY 10804
(800) 232-4773
(914) 632-3925
(914) 235-0615 (fax)
esr1@iona.bitnet
1,2,7

Sudden Infant Death Syndrome (SIDS)

See also: Bereavement Support

National Sudden Infant Death Syndrome Resource Center
8201 Greensboro Dr, Ste 600
McLean, VA 22102
(703) 821-8955
(703) 821-2098 (fax)
1,2,7

Sudden Infant Death Syndrome Alliance
1314 Bedford Ave, Ste 108
Baltimore, MD 21208
(800) 221-7437
(410) 653-8226
1,6,7,8,9

Sudeck Atrophy

See: Reflex Sympathetic Dystrophy Syndrome

Sulfatidosis

See: Hearing Impairments, Ichthyosis, Leukodystrophy, Tay-Sachs Disease

Syringobulbia

See: Syringomyelia

Syringomyelia

See also: Arnold-Chiari Malformation

American Syringomyelia Alliance Project
PO Box 1586
Longview, TX 75606-1586
(800) 272-7282
(903) 236-7079
(903) 757-7456 (fax)
1,3,4,6,10

Canadian Syringomyelia Network
65 Huntingdale Blvd, #1607
Scarborough, ON CAN M1W 2P1
(416) 498-8097
(416) 750-8197 (fax)
1,4,6,7,8

Tangier Disease

See: Tay-Sachs Disease

Tay Syndrome

See: Ichthyosis

Tay-Sachs Disease

National Tay-Sachs and Allied Diseases Association
2001 Beacon St, Ste 204
Brookline, MA 02146
(617) 277-4463
(617) 277-0134 (fax)
1,2,3,4,5,6,7,8,9,10; lending library

Tetrasomy 15

See: Chromosome 15 Disorders

Tetrasomy 18

See: Chromosome 18 & 13 Disorders

Thalassemia

See: Cooley's Anemia

Thrombocytopenia

See: Evans Syndrome

Thrombocytopenia Absent Radius (TAR) Syndrome

Thrombocytopenia Absent Radius Syndrome Association
212 Sherwood Dr, RD 1
Linwood, NJ 08221-9745
(609) 927-0418
1,4,7,10

Thyroid Disorders

See also: Graves Disease

Thyroid Foundation of Canada
1040 Gardeners Rd, Ste C
Kingston, ON CAN K7P 1R7
(613) 634-3426
(613) 634-3483 (fax)
1,5,6,7,9,10

Tourette Syndrome

See also: Attention Deficit Disorder, Obsessive-Compulsive Disorder

Tourette Syndrome Association
42-40 Bell Blvd
Bayside, NY 11361-2861
(800) 237-0717
(718) 224-2999
(718) 279-9596 (fax)
1,2,3,5,6,7,9,10

Tourette Syndrome Foundation of Canada
238 Davenport Rd, Box 343
Toronto, ON CAN M5R 1J6
(800) 361-3120 (Canada only)
(416) 351-7757
(416) 351-9267 (fax)
1,2,3,4,5,6,7,8,9,10; camp

Tracheoesophageal Fistula (TEF)

See: VATER Association

Tracheostomy

Tracheostomy Support Group
144 Elmwood
Barberton, OH 44203
(216) 745-4392
4,7,8,10

Treacher Collins Syndrome

See also: Craniofacial Disorders

Treacher Collins Foundation
PO Box 683
Norwich, VT 05055
(800) 823-2055
(802) 649-3050
1,2,3,4,6

Tremor

International Tremor Foundation
833 W Washington Blvd
Chicago, IL 60607
(312) 733-1893
1,2,4,7,8,9,10

Trichotillomania

See: Obsessive-Compulsive Disorder

Trisomy 13, 18 & Related Disorders

See: Chromosome 18 & 13 Disorders

Tuberous Sclerosis

See also: Autism, Epilepsy, Learning Disabilities

National Tuberous Sclerosis Association
8000 Corporate Dr, Ste 120
Landover, MD 20785
(800) 225-6872
(301) 459-9888
(301) 459-0394 (fax)
ntsa@capcon.net
1,2,3,4,5,6,7,8,9,10; blood and tissue donations; audiotapes

Turcot Syndrome

See also: Brain Tumors, Cancer

Turcot Syndrome and Hereditary Medulloblastoma
c/o Dr. Daniel Lasser
OB/GYN
Columbia Univ College of Physicians
630 W 168th St
New York, NY 10032
(212) 305-6784
(212) 305-3869 (fax)
DML1@columbia.edu
7

Turner Syndrome

See also: Growth Disorders

Turner's Syndrome Society—Canada
7777 Keele St, Fl 2
Concord, ON CAN L4K 1Y7
(800) 465-6744
(905) 660-7766
(905) 660-7450 (fax)
1,2,3,4,5,6,7,10

Turner's Syndrome Society of the US
15500 Wayzata Blvd, #768-214
811 12 Oak Ctr
Wayzata, MN 55391
(612) 475-9944
(612) 475-9949 (fax)
LGTesch@cerfnet.com
1,2,3,4,5,6,7,8,9,10; scholarship program to help girls with Turner syndrome attend national conference

Urea Cycle Disorders

National Urea Cycle Disorders Foundation
PO Box 32
Sayreville, NJ 08872
(800) 386-8233
1,4,6,7,10

Urostomy

See: Ostomy

Urologic Disorders

See: Incontinence, Kidney Disorders

Usher Syndrome

See also: Hearing Impairments, Retinitis Pigmentosa, Visual Impairments

Usher Family Support
c/o Helen Anderson
4918 42nd Ave S
Minneapolis, MN 55417
(612) 724-6982
1,4,7,10

Vascular Malformations

See also: Hemangioma; Hemorrhagic Telangiectasis, Hereditary; Klippel-Trenaunay Syndrome; Moyamoya Disease; Nevi, Giant Congenital; Sturge-Weber Syndrome

National Vascular Malformations Foundation
8320 Nightingale
Dearborn Heights, MI 48127
(313) 274-1243 (voice/fax)
1,4,6, 7

VATER Association

See also: Anorectal Malformations

TEF/VATER Support Network
c/o Greg and Terri Burke
15301 Grey Fox Rd
Upper Marlboro, MD 20772
(301) 952-6837
1,2,4,5,7,10

Velo-Cardio-Facial Syndrome

See also: Attention Deficit Disorder, Cleft Palate, DiGeorge Syndrome

Velo-Cardio-Facial Syndrome Parent Support Group
110-45 Queens Blvd
Forest Hills, NY 11375-5501
(718) 261-8049
(718) 261-7346 (fax)
4,7

Ventilator Use

Citizens for Independence in Living & Breathing
78 Golfwood Hghts
Etobiocolce, ON CAN M9P 3M2
(416) 244-2248 (voice/fax)
3,4,6,7,8

International Ventilator Users Networks
5100 Oakland Ave, #206
St Louis, MO 63110
(314) 534-0475
(314) 534-5070 (fax)
1,2,4,7

Vestibular Disorders

See also: Balance Disorders & Dizziness

Vestibular Disorders Association
PO Box 4467
Portland, OR 97208-4467
(800) 837-8428
(503) 229-7705
(503) 228-8665 (TTY)
(503) 229-8064 (fax)
Junder@teleport.com
1,2,3,4,57,10

NATIONAL RESOURCES FOR SPECIFIC DISABILITIES AND CONDITIONS

Visual Impairments

See also: Albinism, Macular Diseases, Retinitis Pigmentosa, Retinoblastoma, Retinopathy of Prematurity, Septo-Optic Dysplasia, Stargardt Disease, Usher Syndrome

American Council of the Blind
1155 15th St NW, Ste 720
Washington, DC 20005
(800) 424-8666 (9–5:30 EST)
(202) 467-5081
1,2,6,7,8

American Foundation for the Blind
11 Penn Plaza
New York, NY 10001
(800) 232-5463
(212) 507-7600
afbinfo@afb.org
1,2,3,7,8,10

American Printing House for the Blind
1839 Frankfort Ave
PO Box 6085
Louisville, KY 40206-0085
(800) 223-1839
(502) 895-2405
(502) 895-1509 (fax)
1,2,3

Blind Children's Center
4120 Marathon St
Los Angeles, CA 90029
(800) 222-3566
(800) 222-3567 (CA only)
1,2,3,4,7

Blind Children's Fund
2875 Northwind Dr
East Lansing, MI 48823-5040
(517) 333-1725
(517) 333-1730 (fax)
1,2,3,4,6,7,8

Canadian National Institute for the Blind
1929 Bayview Ave
Toronto, ON CAN M4G 3E8
(416) 486-2500
(416) 480-7417 (TTY)
(416) 480-7699 (fax)
7

Council of Citizens with Low Vision International
5707 Brockton Dr, Ste 302
Indianapolis, IN 46220-5481
(800) 733-2258
(317) 254-1332
(317) 251-6588 (fax)
PatPrice@aol.com
1,5,6; scholarships

National Association for Parents of the Visually Impaired
PO Box 317
Watertown, MA 02272-0317
(800) 562-6265
(617) 972-7441
(617) 972-7444 (fax)
1,2,4,5,6,7,8,10

National Association for Visually Handicapped
22 W 21st St, 6th Fl
New York, NY 10010
(212) 889-3141
(212) 727-2931 (fax)
1,2,7

National Organization of Parents of Blind Children
1800 Johnson St
Baltimore, MD 21230
(410) 659-9314
(410) 752-5011 (BBS)
(410) 685-5653 (fax)
1,2,3,4,5,6,7,8

Prevent Blindness America
500 E Remington Rd
Schaumburg, IL 60173-4557
(800) 331-2020
(708) 843-2020
(708) 843-8458 (fax)
1,2,3,5,6,7,9

Recording for the Blind
20 Roszel Rd
Princeton, NJ 08540
(609) 452-0606
(609) 520-7990 (fax)
1,5,7,8,9

The Lighthouse
111 East 59th St
New York, NY 10022
(800) 334-5497
(212) 821-9200
(212) 821-9713 (TTY)
(212) 821-9705 (fax)
1,2,3,7,8

VIEWS for the Visually Impaired
95 Wareside Rd
Etobicoke, ON CAN M9C 3B5
(416) 620-1410
(416) 620-1472 (fax)
1,2,3,4,5,6,7,8,9,10

Vitiligo

National Vitiligo Foundation
PO Box 6337
Tyler, TX 75711
(903) 534-2925
(903) 534-8075 (fax)
73071.33@compuserve.com
1,2,5,9,10

Von Hippel-Lindau Syndrome

See also: Ataxia, Balance Disorders & Dizziness, Brain Tumors, Visual Impairments

Von Hippel-Lindau Syndrome Family Alliance
171 Clinton Rd
Brookline, MA 02146
(800) 767-4845
(617) 232-5946
(617) 734-8233 (fax)
VHL@pipeline.com
1,2,3,4,5,6,7,8,9,10,11 (BBS goes online Jan. 15, 1995; call for details); outpatient clinics in US and other countries

Von Recklinghausen Disease

See: Neurofibromatosis

Weber Syndrome

See: Sturge-Weber Syndrome

Wegener Granulomatosis

See also: Autoimmune Disorders, Granulomatous Disease

Wegener's Granulomatosis Support Group
PO Box 1518
Platte City, MO 64079-1518
(800) 277-9474
(816) 858-4444 (fax)
1,2,3,4,5,6,7,10

Werdnig-Hoffman Disease

See: Spinal Muscular Atrophy

Whistling Face Syndrome

See: Freeman-Sheldon Syndrome

White Matter Disorders

See: Leukodystrophy

Williams Syndrome

See also: Autism, Attention Deficit Disorder, Growth Disorders, Heart Disorders, Learning Disabilities

CAWS: Canadian Association for Williams Syndrome
c/o Cathy Wilson
PO Box 2115
Vancouver, BC CAN V6B 3T5
(403) 887-5257
1,4,5,6,7,9,10; clinic in Toronto

Williams Syndrome Association
PO Box 297
Clawson, MI 48017-0297
(810) 541-3630
(810) 541-3631 (fax)
1,2,3,4,5,6,7,9,10; regional conferences, summer camp

Wilson's Disease

See: Liver Disorders

Wiskott-Aldrich Syndrome

See: Immune Disorders

Key to Services

1. Periodical/newsletter
2. Other publications
3. Videos
4. Networking/matching
5. Local chapters
6. National conferences
7. Referrals to local resources
8. National advocacy efforts
9. Fund research
10. Maintain registry of individuals with this condition
11. Electronic bulletin board (BBS)

Wolf-Hirschhorn Syndrome (4p–)

Wolf-Hirschhorn Syndrome Support Group and Newsletter
5536 Virginia Ct
Amherst, OH 44001
(216) 282-1460
1,4,6

4p– Parent Network
c/o Becky & Tom Richardson
3200 Rivanna Ct
Woodbridge, VA 22192
(703) 491-0309
1,4,6,10

Wolf-Parkinson-White Syndrome

See: Growth Disorders

Wolman Syndrome

See: Tay-Sachs Disease

X-Linked Centronuclear Myopathy

See: Myotubular Myopathy

X-Linked Myotubular Myopathy

See: Myotubular Myopathy

Xeroderma Pigmentosum

Xeroderma Pigmentosum Registry
c/o W. Clark Lambert, M.D.,Ph.D
UMD–NJ Medical School
Dept of Pathology, Rm C-520
185 S Orange Ave
Newark, NJ 07103-2714
(201) 982-6255
(201) 982-7293 (fax)
7,10

Zellweger Syndrome

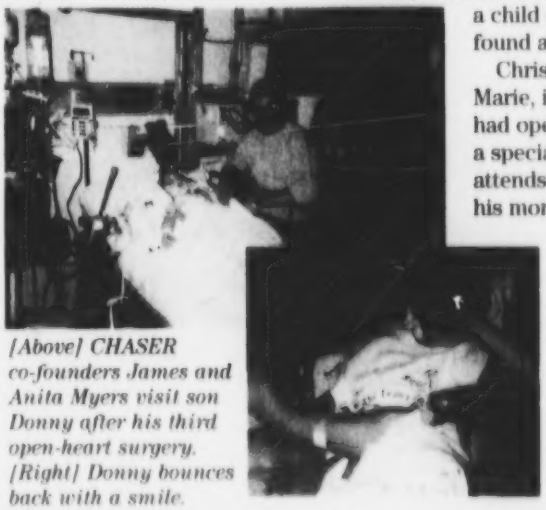
See: Leukodystrophy

No Longer Alone

Matching organizations help parents find each other

Julie Gordon wanted to help people avoid feeling as she did when she left the hospital with her firstborn child and no answers. Her baby, Jessica, had suffered severe brain damage during delivery and after all the tubes, wires and seizures, was finally placed in her mother's arms with the doctor's proclamation, "Wait and see... We can't fix her."

When Jessica was six, Julie started MUMS, Mothers United for Moral Support, an international matching organization that now, after 15 years, has more than 5,200 members. Julie and volunteer workers keep a database of children, diagnosed and undiagnosed, to match parents with each other for support.



[Above] CHASER co-founders James and Anita Myers visit son Donny after his third open-heart surgery. [Right] Donny bounces back with a smile.

Like most matching organizations, MUMS began with a phone call. After Jessica was diagnosed with cerebral palsy, Julie got the names of three other mothers whose children also had cerebral palsy. They met for the first time around Christmas, and talked late into the night.

The group grew by word of mouth, with people coming from a 30-mile radius of Julie's home in Green Bay, Wisconsin. When her database went from index cards to a computer, a national information clearinghouse in South Carolina began to refer people to her from around the country, and the local support group became a nationwide network.

Clearinghouses and groups such as NORD (National Organization for Rare Disorders) and the Alliance for Genetic Support Groups are good resources for information about specific disabilities and referrals to existing groups. However, such groups do not keep track of children who are undiagnosed. And many parents have children with rare conditions, more than one disability or unique family situations like twins or adoption. Matching groups, both national and international (see sidebar), can help.

Common Ground

Christine Barr and Nancy Bush each have a child with a chromosome 7q deletion. Christine, who lives on Long Island, New York, and Nancy, who lives in Driggs, Idaho, met through a *Search* letter in *Exceptional Parent* magazine in 1992. That year, they and four other parents started Chromosome Deletion Outreach, a matching group for all conditions caused by chromosomal deletions, additions and inversions. The group has grown from 20 to 275 members.

At first, Christine wanted to talk to a parent who had a child exactly like hers. Instead, she found a lifelong friend.

Christine's five-year-old daughter, Tyler Marie, is just starting to use a walker, had open-heart surgery and is enrolled in a special school. Nancy's son, Daniel, 10, attends public school and moves, says his mom, "at the speed of light." Both are non-verbal.

"No two children are exactly the same," said Christine, who sees common experiences shared by all parents of children with disabilities. "We've all been through learning that there is something wrong with our child, the hurt, the disappointment, the fear."

Nancy added, "This group is the one place where we can brag about our kids."

Sometimes a support group will start from a match, but some conditions are so rare, there will never be enough parents to form a separate group. "There are more common chromosomal anomalies like Down syndrome and Trisomy 18, but there are also conditions even more rare than chromosome 7 deletions," said Christine. "So, we're kind of all together."

According to Nancy, the group's greatest accomplishment has been getting professionals to refer families to them and to other matching organizations. She hopes for the day when professionals will stop telling parents, "You are the only one," and start telling them, "There is a place you can go."

A Family Affair

Like many other parents of children with disabilities, Anita and James Myers left the hospital after the birth of their second son and entered the information void. Within five hours of a normal birth, their son, Donny, was carted off to intensive care and diagnosed with hypoplastic left heart syndrome. The Myers were given less than 20 minutes to decide on a hospital transfer and

surgery. They were told not to get their hopes up.

After Donny's surgery, they were not told much of anything.

"We had to become our own detectives," said James, who said often one phone call—even a long shot—can lead to another.

In 1993, when Donny was three years old, the Myers started CHASER—Congenital Heart Anomalies Support, Education and Resources—now an international matching organization for parents of children who have heart disorders along with any additional disabilities.

The Myers live in Swanton, Ohio, a suburb of Toledo. They call themselves "everyday people" from "small-town, USA." But, "into the wee hours of the morning," Anita and James are making matches across the globe, sharing resources with a doctor in Israel or a parent in Japan, putting out a newsletter, telephoning, typing or faxing. Their sons Danny, 9, and Donny, now almost 5, help fold and staple. "It's a special family time," said James.

According to Robin Twitty, the Myers have spread the spirit of family far. Her five-year-old daughter, Kaitlin, has CHARGE syndrome, a group of associated disorders which often includes heart defects. Through CHASER, Robin has met parents of older children who help to demystify her daughter's future.

"You don't want to talk about the bad things, like how close we came to losing her, but when you do, and someone says 'Yeah, we went through that too,' you really start talking," she said.

Recently, another CHASER mom surprised Robin by driving two and half hours to "drop by" the hospital where Kaitlin was recovering from surgery. "You feel this connection, like they live next door," Robin said.

Someone To Turn To

Many matching organizations across the country and world are run by parents who remember all too well the lonely drives to and from medical centers and hospitals. And, as more matches are made, new support groups continue to form. Joan Weiss, executive director of the Alliance of Genetic Support Groups, sends people free information kits on how to start their own groups. You don't need a college degree, she said, but you do need time, a supportive family, a big kitchen table and, "the ability to look into the future and see how important it is that other people have someone to turn to."

—Andrea Kamens

Matching Resources

The following organizations do parent-to-parent matching and refer parents to local resources. They are in contact with each other and other groups worldwide. Some charge a nominal membership fee. Each listing is followed by a brief description of the conditions with which the group deals.

Association of Birth Defect Children
827 Irma Ave
Orlando, Florida 32803
(800) 313-2232 (answering machine)
(407) 245-7035
All birth defects, especially those linked to exposure to environmental toxins such as medication, pesticides, radiation and Agent Orange; new research being done on Gulf War babies.

Association for Neurometabolic Disorders
Cheryl Volk
5223 Brookfield Ln
Sylvania, OH 43560-1809
(419) 885-1497
Glactosemia, Maple Syrup Urine disease, Biotinidase, PKU and other metabolic disorders.

CHASER: Congenital Heart Anomalies Support, Education and Resources
Anita and James Myers
2112 N Wilkins Rd
Swanton, OH 43558
(419) 825-5575
(419) 825-2880 (fax)
Congenital heart defects and acquired heart disorders; any disability accompanied by heart problems.

Chromosome Deletion Outreach
PO Box 532
Center Moriches, NY 11934
(516) 878-3510 or (208) 354-8550
Chromosome deletions, additions and inversions.

Contact A Family
c/o Harry Marsh
170 Tottenham Court Rd
London W1P OHA
England
(01144) 71-383-5555
All disabilities.

MUMS: Mothers United for Moral Support
c/o Julie Gordon
150 Custer Ct
Green Bay, WI 54301-1243
(414) 336-5333
(414) 339-0995 (fax)
All disabilities.

National Parent-to-Parent Support and Information System
c/o Kathleen Judd
PO Box 907
Blue Ridge, GA 30513
(800) 651-1151 (V/TTY)
(706) 632-8822 (V/TTY)
(706) 632-8830 (fax)
Special health care needs and rare disorders.

Rare Chromosome Disorder Group
Edna Knight
Harrow Weald
160 Locket Rd
Middlesex
England
(01144) 81-963-3557
Rare chromosomal disorders.

Search & Respond
c/o Exceptional Parent
209 Harvard St, Ste 303
Brookline, MA 02215
(617) 730-5800
(617) 730-8742 (fax)
All disabilities.

Other Resources

The following groups provide information on specific disabilities and refer parents to support groups and other resources. They may provide some matching.

Alliance of Genetic Support Groups
Joan O. Weiss
35 Wisconsin Circle, Ste 440
Chevy Chase, MD 20815-7015
(800) 336-4363
(301) 654-0171 (fax)
Provides free kits on how to start a support group and information on genetic disorders; no direct parent-to-parent matching.

Lethbridge Society for Rare Diseases
#2-740 4th Ave S
Lethbridge, Alberta T1J ON9
Canada
(403) 329-0665
(403) 329-0089 (fax)
Provides literature on rare disorders (using the database from NORD) and does parent-to-parent matching within Canada.

NORD: National Organization for Rare Disorders
PO Box 8923
New Fairfield, CT 06812-1783
(800) 999-6673 (voice)
(203) 746-6927 (TTY)
(203) 746-6481 (fax)
A confederation of volunteer agencies. Sends literature with information on specific rare disorders and makes referrals to support groups or matching groups. Paid members have access to direct parent networking. Membership $25/yr.

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Call or write Bryan Efron, Ph.D., Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.

new england villages inc.

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Circle # 21

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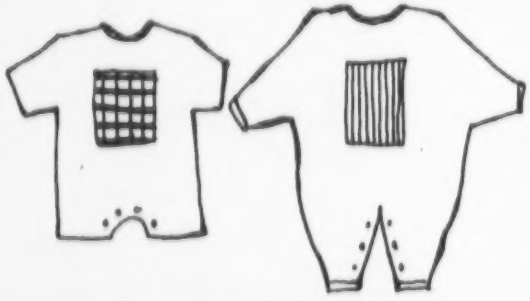

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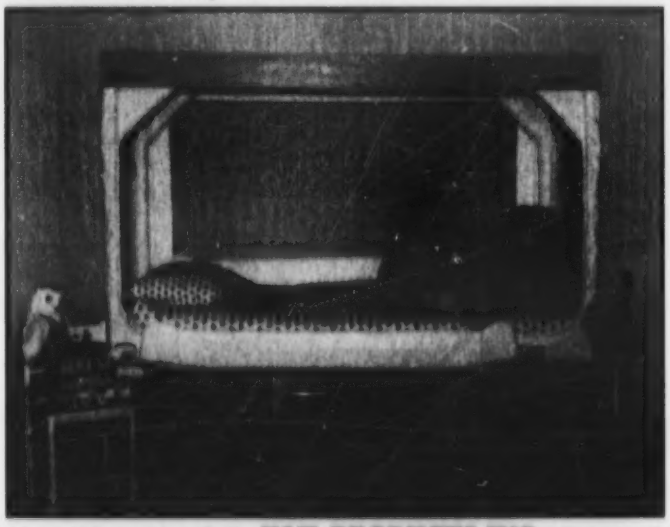

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1-800-235-VAIL

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Centerville, Ohio 45459
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FAX 1-513-433-0779

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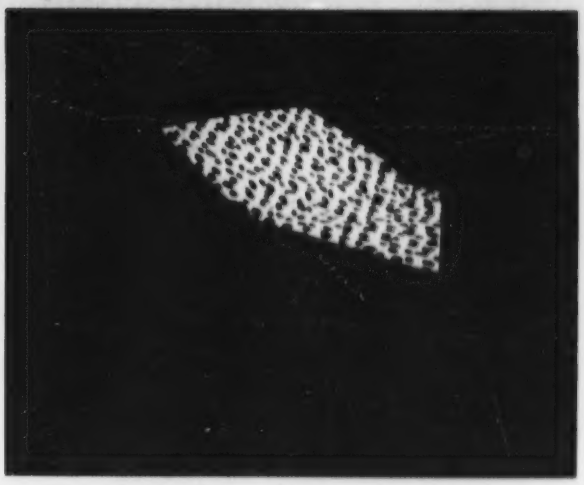

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* Based on research by TMI.

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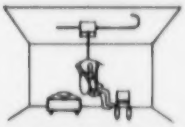

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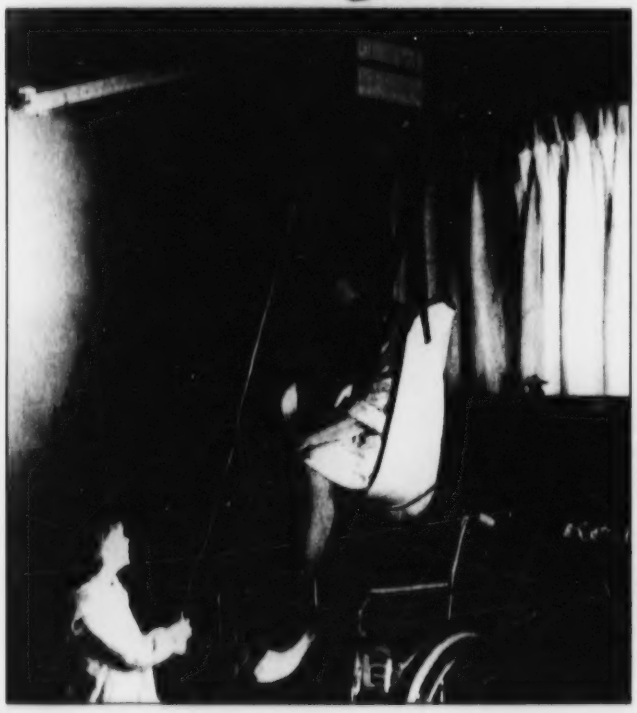
  Vertical & horizontal motion at the push of a button.
- **Battery operated & no maintenance!**
  Batteries are automatically recharged each time the lift is used.



Helping You Achieve Greater Mobility

Barrier Free Lifts, Inc.
P.O. Box 4163 • Manassas, VA 22110
(703) 361-6531 • FAX (703) 361-7861
1-800-582-8732

Circle # 39

Meeting Street Center

Assistive Technology Center

The mission of Meeting Street Assistive Technology Center is to enable people to maximize their independence in school, work, home and community environments through the use of the most appropriate assistive devices available. For more information or to make a referral for an evaluation, please contact Kris Auger at (401) 438-9500 ext. 299. (401) 438-9500 ext. 260

667 Waterman Avenue, East Providence, Rhode Island, 02914
(401) 438-9500 (401) 438-3760 FAX (401) 438-3690 TDD

Meeting Street Center is the local affiliate for the National Easter Seal Society

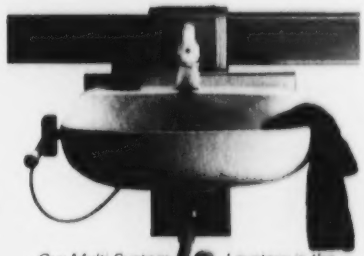
TEACHING SKILLS TOUCHING HEARTS CHANGING LIVES!

Circle # 83

How do you take a sit-down shower? How does a sink go up and down? How do astronauts go to the bathroom?

Talk about your awkward situations. Astronauts first strap themselves in with foot and thigh restraints. They've got a toilet bowl but no water. Instead, 12 air jets underneath the seat propel everything into a storage tank.

Hot water might just be the best problem solver around. This comfortable, movable, contoured shower chair lets you soak it in without a care. Our Ceratherm shower with thermostatic control makes you feel even more at ease.



Our Multi-System Lavatory is the closest anyone's come to a portable sink. It adjusts very quickly to accommodate wheelchairs, those with back trouble, or anyone tall, short or in-between. It even slides to the left or to the right.

Everyone goes to the bathroom. In very different circumstances. Still, it should always feel inviting. Private. Relaxing. It should be a chance to feel free. To that end, American Standard offers the biggest choice of smartly designed, stunningly designed accessible products anywhere. We'll also answer all your questions. Even if we have to ask NASA. Just call us at 1-800-524-9797, Ext. 469. **American Standard**

Circle # 175

©1994 American Standard Inc.

SPECIAL INTRODUCTORY SAVINGS OFFER!

Plus

"REAL" underwear just like "Mommy's & Daddy's"
but with
special moisture-proof "Dri-Gard Barrier"
with
Pads that *Gel* to keep wetness inside the pad!

PREVENT® *Plus*

Bladder Protection

For Boys and Girls

TRAINING SYSTEM

- **Panties & Briefs *plus***
- **"T" Shaped Pad for custom fit**
- ***Daytime protection***

Offer # 1 ... ☐	
Package includes:	
One (1) Girls or Boys Training Pants	
One (1) Bag 20 Training Pads	
Normal Retail Price of these items..	$16.50
Special introductory savings	- 1.50
You Pay Only	$15.00

Offer # 2 ... ☐	
Package includes:	
Three (3) Girls or Boys Training Pants	
Three (3) Bags 60 Training Pads	
Normal Retail Price of these items..	$49.50
Special introductory savings	- 6.00
You Pay Only	$43.50

Name _____
Address _____
City _____
State/Zip _____

Please, Rush My Introductory Offer of Prevent Plus.
(Please check the offer you desire)
☐ Offer #1 - $15.00 + $3 ship.
☐ Offer #2 - $43.50 + $3 ship.

Pant SIZE CHART		*Waist*	*Hips*	*Weight*
Boys	*4T*	*20-21"*	*19-20"*	*28-38 lb.*
Boys	*6*	*21-22"*	*21-23"*	*39-49 lb.*
Boys	*8*	*22-23"*	*24-26"*	*50-59 lb.*
Girls	*4T*	*21½-22"*	*19-20"*	*28-38 lb.*
Girls	*6*	*22½-23"*	*21-23"*	*39-49 lb.*
Girls	*8*	*23½-24"*	*24-26"*	*50-59 lb.*

(Please check the style and size required)
Style: Boys ____ Girls ____
Size: 4T____ 6 ____ 8 ____

Enclosed please find a ___check or _____
Money Order in the amount of $_____.
Sorry no COD's. payable to:
HUMANICARE INTERNATIONAL
1471 Jersey Avenue,
North Brunswick, New Jersey 08902
EP195

Circle # 90

We Can Make A Difference!

"Now I can see my beautiful daughter flourishing and making progress that I never thought possible! Thank goodness for a place like this school."

–Parent
Intensive Program

When you feel that there isn't any answer, when you feel there are no other options available, **DON'T GIVE UP!** Our Intensive Program makes a difference for students with serious, challenging behaviors. We accept students who require the specialized care that other schools just cannot provide. We give our students state-of-the-art educational and residential programs free of painful aversives and excessive medication.

Many of our students arrive at the New England Center for Autism after having had a long history of rejection and failure. With us they receive intensive, positive, behaviorally oriented treatment that focuses on developing the coping skills and appropriate behaviors which enable them to live and work successfully with minimum support. Intensive Program students participate in the full range of academic, community, and recreational activities provided for all of our students.

*Let **The New England Center for Autism** make a positive difference in your child's life.*

For more information on our Intensive Program, please contact **Catherine M. Welch, MEd, Director of Admissions.**

The New England Center For Autism

The New England Center for Autism
33 Turnpike Road, Southboro, MA 01772
(508) 481-1015
Just 20 miles from Boston

51

Circle # 76

EVERY YEAR WE INTRODUCE THOUSANDS OF MOTORISTS TO THE JOYS OF TRAFFIC JAMS, POTHOLES AND PEOPLE WHO DRIVE WITH THEIR BLINKERS ON.

AND WE'RE NOT THE LEAST BIT SORRY.

In fact, we couldn't be more pleased. We know that for most people, the ability to get out on the road--even with a few minor irritations—is an essential part of an active and independent lifestyle.

That's why, years ago, we became the first automotive company to establish an assistance program for people with disabilities. Since then, Chrysler's Automobility Program (formerly the Physically Challenged Assistance Program, or P-CAP) has helped thousands of people—drivers and passengers alike—achieve a lifestyle of independence and freedom that may not have been possible otherwise.

We'd like to tell you more about the program details. Cash reimbursements of up to $1,000 for adaptive driving or passenger aids installed on new Ram Vans and Wagons; up to $750 on all other new Chrysler Corporation cars, trucks and minivans. A friendly, knowledgeable Automobility Support Center to help answer all your questions. And Chrysler Credit financing to qualified buyers.

AUTO PROGRAM
CHRYSLER CORPORATION

All topped by more experience assisting people with disabilities than any other automotive company. So call us, or contact your local Chrysler Corporation dealer, for more information. And let us show you how Automobility can contribute to an active, mobile lifestyle. You won't be the least bit sorry.

For more information and a free video on the Automobility Program, call us at **(800) 255-9877**.

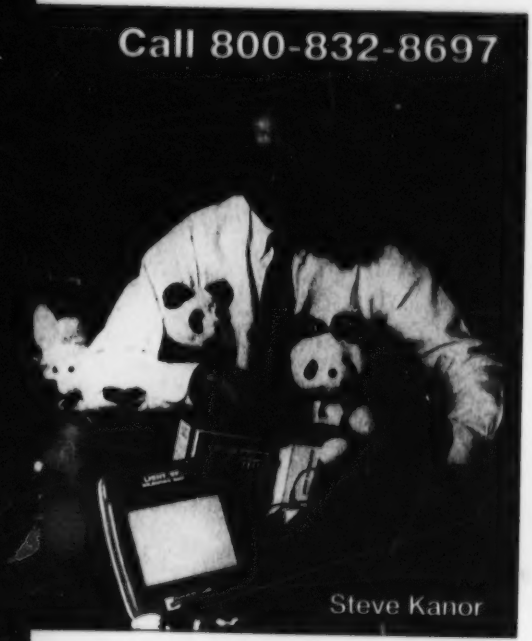
Circle #146

Toys for Special Children

The people of Toys for Special Children have sought to create a new world of play for children with disabilities, through the development of specially adapted toys, capability switches, activity centers, augmentative communication aids, and countless other special devices.

Vibrating Light

Call 800-832-8697


Steve Kanor

Special Service

We offer many standard technical solutions for people with disabilities. We realize that for some, special adaptions are needed. Please call us so that we can discuss fabricating custom equipment for your special requirements.

"Dr. Kanor's devices have benefits beyond words"

-The New York Times-
Oct. 20th, 1991

A unique resource for technology which can be used to increase, maintain, or improve functional capabilities of individuals with disabilities.

The Cooper Car

To get your catalog call or write to:
Toys for Special Children
385 Warburton Avenue
Hasting-on-Hudson, NY 10706
800-832-8697

Circle # 160

Parent Training & Information Centers

Parent Training and Information programs (PTIs) are funded by the Division of Personnel Preparation, Office of Special Education Programs in the U.S. Department of Education. Their stated mission is "to provide training and information to parents to enable [them] to participate more effectively with professionals in meeting the educational needs of children with disabilities."

PTIs can help parents to:

- *Understand their children's specific needs.*
- *Communicate more effectively with professionals.*
- *Participate in the educational planning process.*
- *Obtain information about relevant programs, services and resources.*

For more information, contact the National Parent Network on Disabilities (NPND), 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

ALABAMA

Special Education Action Committee
PO Box 161274
Mobile, AL 36616
(800) 222-7322 (voice; AL only)
(205) 478-1208 (V/TTY)
(205) 473-7877 (fax)

ALASKA

Parents As Resources Engaged
540 International Airport Rd
Ste 200
Anchorage, AK 99518
(800) 478-7678 (voice; AK only)
(907) 563-2246 (V/TTY)
(907) 563-2257 (fax)

ARIZONA

Pilot Parent Partnerships
2150 E Highland Ave, #105
Phoenix, AZ 85016
(800) 237-3007 (voice; AZ only)
(602) 468-3001 (V/TTY)
(602) 468-3001 (fax)
(After March 1, 1995, 602 area code changes to 520)

ARKANSAS

Arkansas Disability Coalition
10002 W Markham, Ste B7
Little Rock, AR 72205
(800) 223-1330 (V/TTY; AR only)
(501) 221-1330 (V/TTY)
(501) 221-9067 (fax)

CALIFORNIA

Team of Advocates for Special Kids
100 W Cerritos Ave
Anaheim, CA 92805
(714) 533-8275 (V/TTY)
(714) 533-2533 (fax)

Exceptional Parents Unlimited
4120 N 1st St
Fresno, CA 93726
(209) 229-2000 (voice)
(209) 229-2956 (fax)

Parents Helping Parents
1801 Vicente St
San Francisco, CA 94116
(415) 564-0722 (voice)
(415) 681-1065 (fax)

Parents Helping Parents
3041 Olcott St
Santa Clara, CA 95054
(408) 727-5775 (voice)
(408) 727-0812 (fax)

COLORADO

PEAK Parent Center
6055 Lehman Dr, Ste 101
Colorado Springs, CO 80918
(800) 284-0251 (voice)
(719) 531-9400 (voice)
(719) 531-9403 (TTY)
(719) 531-9452 (fax)

CONNECTICUT

The Family Center/Newington Children's Hospital
181 E Cedar St
Newington, CT 06111
(203) 667-5288 (voice)
(203) 665-7976 (fax)

Connecticut Parent Advocacy Center
5 Church Ln, PO Box 579, Ste 4
East Lyme, CT 06333
(800) 442-2722 (voice; CT only)
(203) 739-3089 (V/TTY)
(203) 739-7460 (fax)

DELAWARE

Parent Information Center of DE
700 Barksdale Rd., Ste 3
Newark, DE 19711
(302) 366-0152 (voice)
(302) 366-0178 (TTY)
(302) 366-0276 (fax)

DISTRICT OF COLUMBIA

COPE
810 Potomac Ave, 1st Fl Rear
Washington, DC 20003
(800) 515-2673 (voice)
(202) 543-6482 (voice)
(202) 543-6682 (fax)

FLORIDA

Family Network on Disabilities
5510 Gray St, Ste 220
Tampa, FL 33609
(800) 825-5736 (V/TTY)
(813) 289-1122 (V/TTY)
(813) 286-8614 (fax)

GEORGIA

Arc of Georgia
2860 E. Point St, Ste 200
East Point, GA 30344
(404) 761-3150 (V/TTY)
(404) 767-2258 (fax)

HAWAII

Learning Disabilities Association of Hawaii
200 N Vineyard Blvd, Ste 310
Honolulu, HI 96817
(800) 533-9684 (V/TTY; HI only)
(808) 536-9684 (V/TTY)
(808) 537-6780 (fax)

IDAHO

Idaho Parents Unlimited
4696 Overland Rd, Ste 478
Boise, ID 83705
(800) 242-4785 (voice; ID only)
(208) 342-5884 (V/TTY)
(208) 342-1408 (fax)

ILLINOIS

Designs for Change
6 N Michigan Ave, Ste 1600
Chicago, IL 60602
(312) 857-9292 (voice)
(312) 857-1013 (TTY)
(312) 857-9299 (fax)

Family Resource Center on Disabilities
20 E Jackson Blvd, Rm 900
Chicago, IL 60604
(800) 952-4194 (voice; IL only)
(312) 939-3513 (voice)
(312) 939-3519 (TTY)
(312) 939-7297 (fax)

INDIANA

The Indiana Parent information Network
4755 Kingsway Dr, Ste 105
Indianapolis, IN 46205
(800) 964-4746 (voice)
(317) 257-8683 (voice)
(317) 251-7488 (fax)

IN*SOURCE
833 Northside Blvd, Bldg #1
South Bend, IN 46617
(800) 332-4433 (V/TTY; IN only)
(219) 234-7101 (V/TTY)
(219) 234-7279 (fax)

IOWA

Iowa Pilot Parents
33 N 12th St, PO Box 1151
Fort Dodge, IA 50501
(800) 952-4777 (voice)
(515) 576-5870 (V/TTY)
(515) 576-8209 (fax)

KANSAS

Families Together
501 Jackson, Ste 400
Topeka, KS 66603
(800) 264-6343 (V/TTY; KS only)
(913) 233-4777 (V/TTY)
(913) 233-4787 (fax)

KENTUCKY

KY-SPIN
2210 Goldsmith Ln, #118
Louisville, KY 40218
(800) 525-7746 (voice)
(502) 456-0923 (V/TTY)
(502) 456-0893 (fax)

LOUISIANA

Project Prompt
4323A Division St., Ste 110
Metairie, LA 70002
(800) 766-7736 (voice)
(504) 888-9111 (voice)
(504) 888-0246 (fax)

PARENT TRAINING & INFORMATION CENTERS

MAINE

Maine Parent Federation
PO Box 2067
Augusta, ME 04338
(800) 870-7746 (V/TTY; ME only)
(207) 582-2504 (voice)
(207) 582-3638 (fax)

MARYLAND

Parents' Place of Maryland
7257 Parkway Dr, Ste 210
Hanover, MD 21076
(410) 712-0900 (V/TTY)
(410) 712-0902 (fax)

Parents' Place of Western Maryland
23 E Frederick St
Walkersville, MD 21793
(800) 735-2258 (TTY only; MD only)
(301) 898-0936 (voice)
(301) 845-2156 (fax)

MASSACHUSETTS

Federation for Children with Special Needs
95 Berkeley St, Ste 104
Boston, MA 02116
(800) 331-0688 (voice; MA only)
(617) 482-2915 (V/TTY)
(617) 695-2939 (fax)

MICHIGAN

CAUSE
313 S Washington Sq, #040
Lansing, MI 48933
(800) 221-9105 (V/TTY; MI only)
(517) 485-4084 (V/TTY)
(517) 485-4145 (fax)

MINNESOTA

PACER Center
4826 Chicago Ave S
Minneapolis, MN 55417
(800) 537-2237 (V/TTY; MN only)
(612) 827-2966 (V/TTY)
(612) 827-3065 (fax)

MISSISSIPPI

Arc/MS-Parent Partners
3111 N State St
Jackson, MS 39216
(800) 366-5707 (V/TTY; MS only)
(601) 366-5707 (V/TTY)
(601) 362-7361 (fax)

MISSOURI

Missouri Parents Act
1722 W South Glenstone, #125
Springfield, MO 65804
(800) 743-7634 (voice; MO only)
(417) 882-7434 (V/TTY)
(417) 882-8413 (fax)

MONTANA

Parents, Let's Unite for Kids
MSU Billings, SPED 267
1500 N 30th
Billings, MT 59101
(800) 222-7585 (voice; MT only)
(406) 657-2055 (voice)
(406) 657-2061 (fax)

NEBRASKA

Nebraska Parents Information & Training Center
3610 Dodge St, Ste 102
Omaha, NE 68131
(800) 284-8520 (V/TTY; NE only)
(402) 346-0525 (V/TTY)
(402) 346-5253 (fax)

NEVADA

Nevada Parent Connection
3380 S Arvil Rd, Ste J
Las Vegas, NV 89102
(702) 252-0259 (voice)
(702) 252-8780 (fax)

NEW HAMPSHIRE

Parent Information Center
PO Box 1422
Concord, NH 03302
(800) 232-0986 (V/TTY; NH only)
(603) 224-7005 (V/TTY)
(603) 224-4365 (fax)

NEW JERSEY

Statewide Parent Advocacy Network
516 North Ave E
Westfield, NJ 07090
(800) 654-7726 (V/TTY; NJ only)
(908) 654-7726 (V/TTY)
(908) 654-7880 (fax)

NEW MEXICO

EPICS
PO Box 788
Bernalillo, NM 87004
(800) 765-7320 (V/TTY)
(505) 867-3396 (V/TTY)
(505) 867-3398 (fax)

Parents Reaching Out to Help
1127 University Blvd, NE
Albuquerque, NM 87102
(800) 524-5176 (V/TTY; NM only)
(505) 842-9045 (V/TTY)
(505) 842-1451 (fax)

NEW YORK

Resource for Children with Special Needs
200 Park Ave S, #816
New York, NY 10003
(212) 677-4650 (voice)
(212) 254-4070 (fax)

Parent Network Center of New York State
452 Delaware Ave
Buffalo, NY 14202
(800) 724-7408 (voice; NY only)
(716) 885-1004 (voice)
(716) 885-3527 (TTY)
(716) 885-9547 (fax)

NORTH CAROLINA

Exceptional Children's Assistance Center
PO Box 16
Davidson, NC 28036
(800) 962-6817 (voice; NC only)
(704) 892-1321 (voice)
(704) 892-5028 (fax)

PARENTS Project
300 Enola Rd
Morganton, NC 28655
(704) 433-2662 (voice)
(704) 438-6457 (fax)

NORTH DAKOTA

Pathfinder Parent Training & Information Center
16th & 2nd Ave SW
Minot, ND 58701
(800) 245-5840 (voice; ND only)
(701) 852-9426 (voice)
(701) 852-9436 (TTY)
(701) 838-9324 (fax)

OHIO

Ohio Coalition for the Education of Children with Disabilities
1299 Campbell Rd, Ste B
Marion, OH 43302
(800) 374-2806 (voice)
(614) 382-5452 (V/TTY)
(614) 382-2399 (fax)

Child Advocacy Center
1821 Summit Rd, Ste 303
Cincinnati, OH 45237
(513) 821-2400 (V/TTY)
(513) 821-2442 (fax)

OKLAHOMA

Pro-Oklahoma/Parent Training and Information Project
1917 S Harvard Ave
Oklahoma City, OK 73128
(800) 759-4142 (V/TTY; OK only, parents only)
(405) 681-9710 (V/TTY)
(405) 685-4006 (fax)

OREGON

Oregon COPE Project
999 Locust St
Salem, OR 97303
(503) 373-7477 (V/TTY)
(503) 373-7477 (fax)

PALAU

Palau Parent Network
PO Box 1583
Koror, PW 76740
(680) 488-1793 (voice)
(680) 488-2830 (fax)

PENNSYLVANIA

Mentor Parent Program
Rte 257, Salina Rd
PO Box 718
Seneca, PA 16346
(800) 447-1431 (voice)
(814) 676-8615 (voice)
(814) 677-4465 (fax)

Parent Education Network
333 East 7th Ave
York, PA 17404
(800) 522-5827 (V/TTY; PA only)
(717) 845-9722 (V/TTY)
(717) 848-3654 (fax)

Arc of Lehigh & Northhampton
1036 N Godfrey St
Allentown, PA 18103
(610) 434-8076 (voice)
(610) 434-6202 (fax)

Parents Union for Public Schools
311 South Juniper St, Ste 602
Philadelphia, PA 19107
(215) 546-1166 (voice)
(215) 731-1688 (fax)

PUERTO RICO

Associacion de Padres por Bienestar de Ninos Impedidos de Puerto Rico
PO Box 21301
Rio Piedras, PR 00928
(809) 763-4665 (voice)
(809) 765-0345 (fax)

RHODE ISLAND

Rhode Island Parent Information Network
500 Prospect St, Wing D
Pawtucket, RI 02860
(800) 464-3399 (voice; RI only)
(401) 727-4144 (voice)
(401) 727-4151 (TTY)
(401) 725-9960 (fax)

SOUTH CAROLINA

Parents Reaching Out to Parents of SC
2712 Middleburg Dr, Ste 102
Columbia, SC 29204
(800) 759-4776 (V/TTY; SC only)
(803) 779-3859 (V/TTY)
(803) 252-4513 (fax)

PARENT TRAINING & INFORMATION CENTERS

SOUTH DAKOTA

South Dakota Parent Connection
3701 W 49th St, Ste 200B
Sioux Falls, SD 57106
(800) 640-4553 (V/TTY; SD only)
(605) 361-3171 (voice)
(605) 361-2928 (fax)

TENNESSEE

Project STEP: Support & Training for Exceptional Parents
1805 Hayes St, Ste 100
Nashville, TN 37203
(800) 280-STEP (voice)
(800) 848-0298 (TTY)
(615) 639-0125 (voice)
(615) 636-8217 (fax)

TEXAS

Special Kids
PO Box 61628
Houston, TX 77208
(713) 643-9576 (voice)
(713) 643-6291 (fax)

Partners Resource Network
1090 Longfellow Dr, Ste B
Beaumont, TX 77706-4889
(800) 866-4726 (voice; TX only)
(409) 898-4684 (V/TTY)
(409) 898-4869 (fax)

Project PODER
2300 West Commerce, Ste 205
San Antonio, TX 78207
(800) 682-9747 (V/TTY)
(210) 222-2637 (V/TTY)
(210) 222-2638 (fax)

UTAH

Utah Parent Center
2290 E 4500 S #110
Salt Lake City, UT 84117
(800) 468-1160 (V/TTY; UT only)
(801) 272-1051 (V/TTY)
(801) 272-8907 (fax)

VERMONT

Vermont Parent Information Center
Chace Mill, 1 Mill St, Box A7
Burlington, VT 05401
(800) 639-7170 (V/TTY; VT only)
(802) 658-5315 (voice)
(802) 658-5395 (fax)

VIRGINIA

PEATC
10340 Democracy Ln, Ste 206
Fairfax, VA 22030
(800) 869-6782 (V/TTY)
(703) 691-7826 (V/TTY)
(703) 691-8148 (fax)

VIRGIN ISLANDS

Inter-Island Parent Coalition
PO Box 4402 Christiansted
St Croix, VI 00802
(809) 778-2275 (voice)

WASHINGTON

Touchstones
6721 51st Ave S
Seattle, WA 98118
(206) 721-0867 (V/TTY)
(206) 721-2422 (fax)

Washington PAVE
6316 S 12th
Tacoma, WA 98465
(800) 572-7368 (V/TTY; WA only)
(206) 565-2266 (V/TTY)
(206) 566-8052 (fax)

STOMP: Specialized Training of Military Parents
12208 Pacific Hwy SW
Tacoma, WA 98499
(800) 298-3543 (voice)
(206) 588-1741 (V/TTY)
(206) 984-7520 (fax)

WEST VIRGINIA

West Virginia Parent Training & Information Center
Colonial Village
104 E Main St, #3B
Clarksburg, WV 26301
(800) 281-1436 (V/TTY; WV only)
(304) 624-1436 (V/TTY)
(304) 624-1438 (fax)

WISCONSIN

Parent Education Project of Wisconsin
2192 S 60th St
West Allis, WI 53219
(800) 231-8382 (voice; WI only)
(414) 328-5520 (voice)
(414) 328-5520 (TTY)
(414) 328-5520 (fax, call before faxing)

WYOMING

Wyoming Parent Information Center
5 N Lobban
Buffalo, WY 82834
(800) 660-9742 (V/TTY; WY only)
(307) 684-2277 (V/TTY)
(307) 684-5314 (fax)

PARENT CENTERS

One size does not fit all!

Children's Specialized Hospital is dedicated exclusively to serving the special needs of children and adolescents.

- Child Study Team
- Learning Disabilities
- Attention Deficit Disorder
- Early Intervention / Pre-School
- Speech and Hearing
- Psychological Services
- Rehab Technology
- Occupational Therapy
- Physical Therapy
- Cognitive Remediation
- Day Hospital
- Recreational Therapy
- Augmentative Communication/ Computer Evaluation
- Nutritional Counseling

Children's Specialized Hospital

MOUNTAINSIDE • PANWOOD • TOMS RIVER
For information in North Jersey call (908) 233-3720 Ext. 8429 or 8439
For information in Central and South Jersey call (908) 914-1100 Ext. 706

Children's Specialized Hospital was among 5% of the nation's hospitals last year awarded "Accreditation with Commendation" — the highest distinction awarded by the Joint Commission on Accreditation of Healthcare Organizations.

Circle # 11

HMS School
For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- *Physical Therapy*
- *Occupational Therapy*
- *Speech and Language Therapy*
- *Communication Aids*
- *Special Education*
- *Music Therapy*
- *Special Medical Attention*
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HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director
HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle # 77

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1-802-655-4755

Circle # 45

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"Sitting and lying have turned to standing and walking—and now even speaking. All skills I was told Lauren would never have. Because of the M.O.V.E. program, Lauren can communicate with others in ways I thought were not possible."
Barbara Ruben, parent
Canoga Park, California

"It's changed our lives. For the first time in four years, I have had to baby-proof my house. I am thrilled!"
Kim Leonetti, parent
Los Angeles, California

The M.O.V.E. curriculum teaches the basic motor skills of sitting, standing, and walking. For more information, contact:

Rifton For People With Disabilities
PO Box 901 • Rifton, NY 12471
800-374-3866/ext 102

Circle # 41

National Rehabilitation Information Center
NARIC
Serving the Nation's Disability Community

The National Rehabilitation Information Center (NARIC)

- information and referral to national and regional disability and rehabilitation resource organizations
- customized database searches for a nominal fee
- publishes: ***Directory of National Information Sources on Disabilities*** **($15); *NARIC Guide to Disability and Rehabilitation Periodicals*** **($15); *Americans with Disabilities Act (ADA): A NARIC Resource Guide*** **($5)**

Contact **NARIC** by mail, phone, fax, BBS, or E-mail 8455 Colesville Road, Suite 935, Silver Spring, MD 20910-3319; **800/346-2742 (V/TT)**, 301/588-9284 (V/TT), 301/587-1967 (Fax); 301/589-3563 (BBS); naric@capaccess.org (E-mail)

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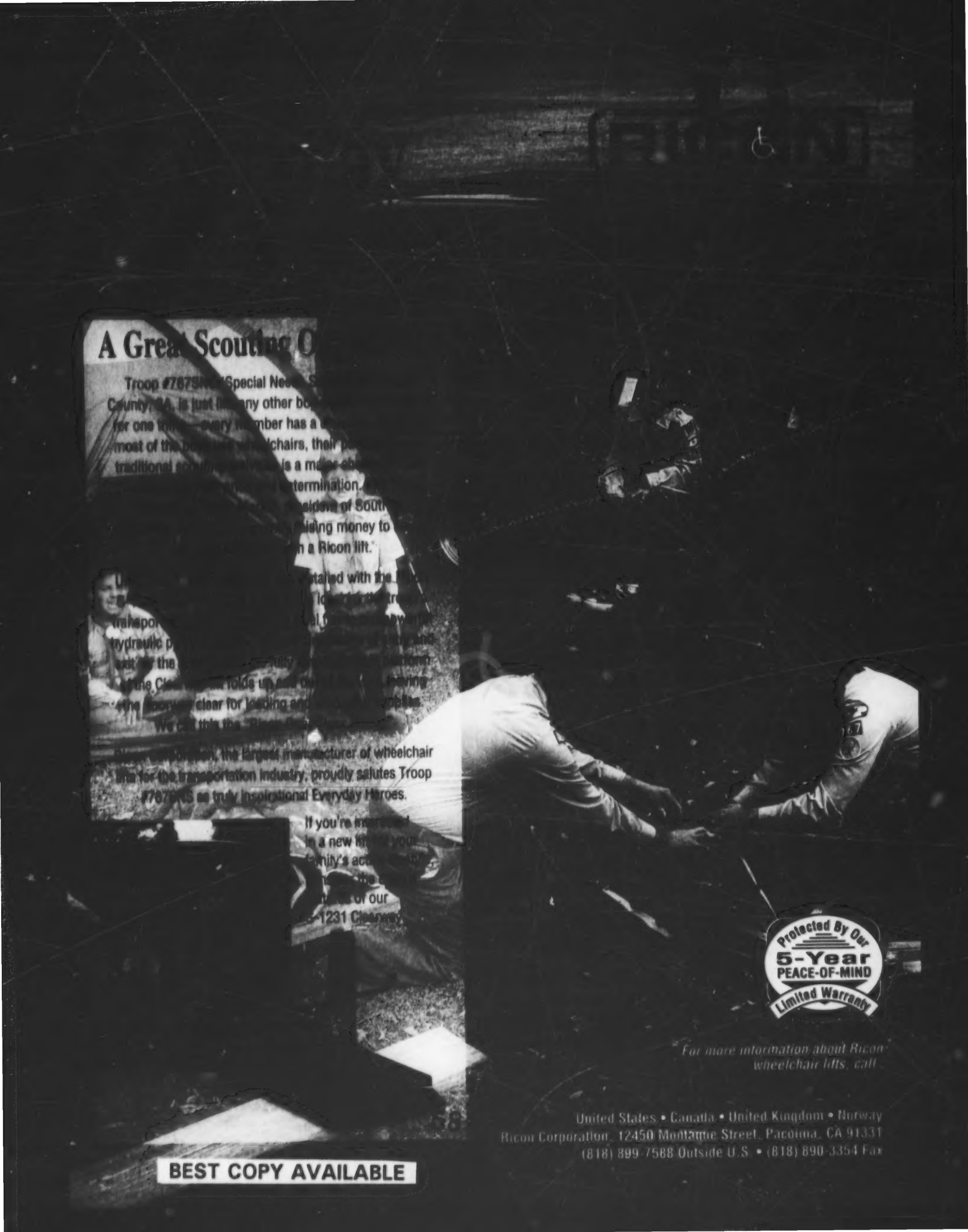
Circle # 59



BEST COPY AVAILABLE

Throwing items, turning over furniture, pulling hair . . . the list continues. For Adam, summers mean more than hayrack rides and swimming. They mean concentrated training, lifeskills, and measurable gains through Heartspring's new Summer Intensive Behavior Program.

Adam, 10, has autism and during his first few days of the summer program at Heartspring, he averaged about 45 acting-out episodes a day. Heartspring staff members developed a plan to interrupt destructive and aggressive behaviors, and to teach Adam more appropriate ways to communicate his needs and frustrations.

They used reinforcers, such as Adam's favorite foods, raisins and apples, and a trip to the local amusement park. A special picture system was developed to help Adam communicate his wants and express his feelings. His program also included around-the-clock extensive behavior management. By the end of the seven weeks, Adam's daily episodes of acting-out had decreased nearly 90 percent.

And what do Adam's parents have to say about the new program? "We were pleased with the growth our son exhibited. Heartspring's new summer program met Adam's needs in a diverse way that no other program we've looked at could."

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Heartspring's Summer Intensive Behavior Program
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Basic Speech at an affordable price!

The Vocal Assistant digitally records 16 messages (any voice, any language). After recording, an individual can play back each message with the touch of a key.

The Vocal Assistant can provide basic speech for individuals who are non-verbal because of

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- Laryngectomy Surgery
- Ventilator Dependency
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Vocal Assistant Model II *New for '95*

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gmr labs
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Sunnyvale, CA 94087
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FAX 408 . 243 . 3731

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RT-10

RT-20

RT-30

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There's a River Tank for every environment.

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Call 1-800-808-8822 for more information or the dealer nearest you.

RIVER TANK SYSTEMS

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- Caring for children from the Mid-Atlantic states ***since 1982***

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Carl Underland, Administrator
1304 Laurel Oak Road • Voorhees, New Jersey 08043-4392
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The Magic Wand Keyboard

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In Touch Systems
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Circle # 102

PARENT TO PARENT PROGRAMS

Parent to Parent (P-P) programs offer a special kind of support to parents who have a child with special needs. Hundreds of active P-P programs in the United States provide emotional and informational support to parents by matching a parent who is referred to the program with an experienced "veteran" parent who has already "been there" and can lend helpful support.

P-P programs originated in Omaha, Nebraska when parents of children with special needs collaborated with a social worker to launch the first Pilot Parents program in the early '70s. The major components of the Pilot Parents model included then—as now—screening and training of veteran parents, carefully made matches between veteran and newly-referred parents and follow-up support. Many P-P programs also offer a range of other support activities like group meetings for education and support, activities for siblings and extended family members, resource libraries, social events and leadership training.

Annual conference grows

P-P programs and families connect with each other at an international conference every other year. Attendance has grown from fewer than 100 to more than 1,100 parents, children and young adults with disabilities and service providers.

The Eighth International Parent to Parent Conference will be held March 29–April 1, 1996 in Albuquerque, New Mexico. For more information, contact Parents Reaching Out, 1127 University NE, Albuquerque, NM 87102, (505) 842-9045.

The Beach Center

Since 1988, the Beach Center on Families and Disability at the University of Kansas has been conducting research on P-P programs and sharing information and resources. For more information, contact The Beach Center on Families and Disability, University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045, (913) 864-7600 (V/TTY), (913) 864-7605 (fax). Listings in this directory were provided by the Beach Center; please send any corrections directly to them.

Using the Directory

In this directory, P-P programs are categorized by state and alphabetized by town or city within each state listing.

ALABAMA

AIM for Infants
Auburn University
Auburn, AL 36849
(205) 844-5943

The Arc of Morgan Cty
2046 Beltline Hwy, Ste 4
Decatur, AL 35601
(205) 355-6192

Parents Support Group
PO Box 1983
Decatur, AL 35602
(205) 350-4502

Special Education Action Committee
PO Box 161724
Mobile, AL 36616-2274
(800) 222-7322 (AL only)

Alabama Deaf-Blind Multihandicapped Association
PO Box 55
Scottsboro, AL 35768
(205) 259-3158

ARIZONA

Pilot Parent Partnerships
1820 North Kadota
Casa Grande, AZ 85222
(602) 836-4830

Pilot Parent Partnerships, Coconino Cty
24 Pine Del Dr
Flagstaff, AZ 86001
(602) 774-0187
(After March 1, 1995, 602 area code changes to 520)

Arizona Pilot Parents
PO Box 697
Ganado, AZ 86505
(602) 755-6107

Sharing Down Syndrome East Valley Parent Support Group
425 E Tremaine
Gilbert, AZ 85234
(602) 926-8685

Pilot Parent Partnerships, Gila Cty
148 Haskins Rd
Globe, AZ 85501
(602) 425-6556

Pilot Parent Partnerships, Mohave Cty
4140 N Irving
Kingman, AZ 86401
(602) 757-5418

Pilot Parent Partnerships, Mohave Cty
2746 Holiday Dr
Lake Havasu City, AZ 86403
(602) 855-1915

Pilot Parent Partnerships, Santa Cruz Cty
1810 W Meadow Hills Dr
Nogales, AZ 85621
(602) 287-2334

Pilot Parent Partnerships
2150 E Highland, Ste 105
Phoenix, AZ 85016-4720
(602) 468-3001

Prescott Chapter, Arizona Pilot Parents
1907 Cedarwood Cir
Prescott, AZ 86301
(602) 468-3001

Pilot Parent Partnerships, Yavapai Cty
2605 Tabosa Dr
Prescott, AZ 86301
(602) 445-7994

Pilot Parent Partnerships
5454 Campo Bello
Sierra Vista, AZ 85635
(602) 378-6763

Pilot Parent Partnerships, Graham & Greenlee Ctys
PO Box 353
Thatcher, AZ 85552
(602) 428-4731

Pilot Parents of Southern Arizona
2600 N Wyatt Dr
Tucson, AZ 85712
(602) 324-3150

Pilot Parent Partnerships, Navajo Cty
PO Box 707
Whiteriver, AZ 85941
(602) 338-4325

Pilot Parent Partnerships, Navajo Cty
PO Box 1148
Winslow, AZ 86047
(602) 289-4323

Pilot Parent Partnerships, Yuma Cty
1321 E 25th
Yuma, AZ 85365
(602) 344-0786

CALIFORNIA

Exceptional Parents Unlimited
4120 N First St
Fresno, CA 93726
(209) 229-2000

Frank D Lanterman Regional Center
Koch-Young Family Resource Ctr
3440 Wilshire Blvd, Ste 400
Los Angeles, CA 90010
(213) 383-1300

California Association for Parents of the Visually Impaired
PO Box 1126
Los Gatos, CA 95031-1126
(909) 945-5619

Parent to Parent Infant Support Group
Children's Hospital of Orange Cty
455 S Main St
Orange, CA 92668
(714) 532-8521

PROUD
PO Box 5822
Orange, CA 92667-5822
(714) 974-6419

Touchstone Support Network
378 Cambridge Ave, Ste K
Palo Alto, CA 94306
(415) 328-4495

PARENT TO PARENT PROGRAMS

PHP: The Family Resource Center
3041 Olcott St
Santa Clara, CA 95054-3222
(408) 727-5775

Valley Parents Support Group
PO Box 5973-272
Sherman Oaks, CA 91413
(818) 902-1616

COLORADO

Child Language Center
University of Colorado
CB-409, Dept CD-SS
Boulder, CO 80309
(303) 492-5375

Peak Parent Center
6055 Lehman Dr, #101
Colorado Springs, CO 80918
(719) 531-9400

Little People of America
7117 E Enclid Dr
Englewood, CO 80111
(303) 740-8555

Effective Parents Project
255 Main St
Grand Junction, CO 81501
(303) 241-4068

Mile High Down Syndrome Association
PO Box 620847
Littleton, CO 80162
(303) 797-1699

Boulder Cty Spokespeople
312 Pikes Peak Pl
Longmont, CO 80501
(303) 776-3413

CONNECTICUT

Parents Available to Help
42 Brookwood Dr
Branford, CT 06405
(203) 488-9640

Cornelia De Lange Syndrome Foundation
60 Dyer Ave
Collinsville, CT 06022-1273
(800) 223-8355

Western Connecticut Association for Human Rights
11 Lake Ave Extension
Danbury, CT 06811
(203) 792-3540

Lower Fairfield Cty Parent to Parent Network
Arc of Greenwich
50 Glenville St
Greenwich, CT 06831
(203) 531-1880

Parent to Parent Network of CT
181 E Cedar St
Newington, CT 06111
(203) 667-5288

Oxford Parent Support Group
10 Whitegate Rd
Oxford, CT 06478-1501
(203) 888-7326

Connecticut Traumatic Brain Injury
1800 Silas Deane Hwy, Ste 224
Rocky Hill, CT 06067
(203) 721-8111

DELAWARE

Parent Information Center
Parent to Parent In Delaware
700 Barksdale Rd, Ste 3
Newark, DE 19711
(302) 366-0152

FLORIDA

Gold Coast Down Syndrome Organization
22626 SW 65
Boca Raton, FL 33428
(407) 451-2163

Parent to Parent, Palm Beach Cty
500 NE Spanish River Rd
Boca Raton, FL 33404
(407) 842-3213

Family Network on Disabilities
852 St Francis St
Brooksville, FL 34601
(904) 544-6433

Family Network on Disabilities, Sumter Cty
5688 Cty 316A
Bushnell, FL 33513
(904) 748-1125

Parent to Parent, Pinellas Cty
1998 Sun Tree Blvd
Clearwater, FL 34623
(813) 461-3614

Parent to Parent of Pinellas Cty
1960E Druid Rd
Clearwater, FL 34624
(813) 462-9606

Parent to Parent Support Group, Bregard & Central Ctys
1943 Furman Ct
Cocoa, FL 32922
(407) 783-5001

Parent to Parent, East Volusia Cty
PO Box 11109
Dayton Beach, FL 32120
(904) 238-3830

Parent to Parent, West Volusia Cty
261 Bayou Vista St
Debary, FL 32713
(407) 668-5968

Parent Support Group, Nassau Cty
2625 McGregor Blvd
Fernandina Beach, FL 32034
(904) 277-1221

Parent Support Group, Hardee & Highlands Ctys
4114 Becton St
Frostproof, FL 33843
(813) 284-3087

Parent Support Group, Lake Cty
905 Hickory Ave
Fruitland Pk, FL 34731
(904) 326-9082

Heart to Heart of Lee Cty
c/o IDEAS
2421 E Mall Dr
Ft Myers, FL 33901
(813) 267-9332

Parent to Parent
100 S Andrews Ave
Ft Lauderdale, FL 33301
(305) 765-6722

Parent Support Group, Lee Cty
7320 Pebblebeach Rd
Ft Myers, FL 33912
(813) 267-9332

Galaxy Center
1901 S 11th St
Ft Pierce, FL 34950
(407) 468-5385

Parent to Parent, St Lucie Cty
5006 Citrus Ave
Ft Pierce, FL 34982
(407) 465-1786

Parent Support Group
University of Florida
Box 100296
Gainesville, FL 32610
(904) 392-7078

Parent to Parent, Alachua Cty
2035 NW 18th Ln
Gainesville, FL 32605
(904) 375-4636

Parent to Parent, Putnam Cty
PO Box 273
Hollister, FL 32147
(904) 328-4107

Family Network on Disabilities, Citrus Cty
922 N Horse Prairie Rd
Inverness, FL 34453
(904) 795-7887

Parent Support Group, Duval Cty
301 W Bay St
Jacksonville, FL 32202
(904) 350-2951

Parent to Parent, Monroe Cty
2824 Fogarty Ave
Key West, FL 33040
(305) 294-8973

Parent to Parent, Columbia Cty
Rte 7, Box 237
Lake City, FL 32055
(904) 497-2300

Parent to Parent, Polk Cty
1405 Windmere Ave
Lakeland, FL 33802
(813) 687-2442

Parent to Parent of Palm Beach
1526 Arabian Dr
Loxahatchee, FL 33470
(407) 790-2548

FAME: Families at Mayport are Exceptional
813 Edson Cir W
Mayport, FL 32222
(904) 249-1161

Parent to Parent of Miami
5555 SW 93rd Ave
Miami, FL 33165
(305) 271-9797

Parent to Parent, Hispanic
9151 SW 6th St
Miami, FL 33174
(305) 223-7379

Parent to Parent, Dade Cty
12350 SW 106th St
Miami, FL 33186
(305) 666-6511

Parent to Parent, Santa Rosa Cty
5890 Cherokee Rd
Milton, FL 32570
(904) 474-5336

Parent to Parent, Pasco Cty
5826 Massachusetts Ave
N Port Richey, FL 34652
(813) 841-0684

Parent to Parent, Collier Cty
4230 Mohawk Pl
Naples, FL 33962
(813) 774-7761

Parent to Parent, Okaloosa Cty
1136 Sandalwood Cir
Niceville, FL 32578
(904) 897-7085

Parent to Parent, Okeechobee Cty
10245 NE 22nd St
Okeechobee, FL 34974
(813) 357-0955

Parent Support Group
5031 Myrtle Bay Dr
Orlando, FL 32829
(407) 273-2630

PARENT TO PARENT PROGRAMS

Parent Support Group, Escambia Cty
3520 Hopestill Rd
Pensacola, FL 32503
(904) 438-9112

Veteran Intensive Care Parents
PO Box 2700, Ste 1N
Pensacola, FL 32513-2700
(904) 474-7656

Special Parents
PO Box 15362
Pensacola, FL 32514
(904) 432-4513

Parent Support Group, Taylor Cty
395 El Camino
Perry, FL 32347
(904) 584-3810

Parent Support Group, Charlotte Cty
2410 Lakeview Blvd
Port Charlotte, FL 33948
(813) 627-4376

Special Beginnings
1700 S Tamiami Trail
Sarasota, FL 34329-3555
(813) 917-2470

Face of Sarasota
PO Box 1424
Sarasota, FL 34230
(813) 955-9250

Parent to Parent, Sarasota & Manatee Ctys
5393 Avenida Del Mare
Sarasota, FL 34242
(813) 349-1861

Family Network on Disabilities, Hernando Cty
8131 Rhambouy Rd
Spring Hill, FL 34606
(904) 544-6433

Parent to Parent, Leon Cty
1839 Miccosukee Rd, #2A
Tallahassee, FL 32308
(904) 877-6968

Family Network on Disabilities
5510 Gray St, Ste 220
Tampa, FL 33624
(800) 825-5736

Parent to Parent, Hillsborough Cty
Mental Health Institute
13301 Bruce B Downs Blvd
Tampa, FL 33612-3899
(813) 974-6168

Parent to Parent, Hillsborough Cty
13958 Fletcher
Tampa, FL 33612
(813) 626-2600

Family Network on Disabilities, Monroe Cty
165 Pk Ave
Tavernier, FL 33070
(305) 852-2592

Parent to Parent Support Group
2945 Elmwood Ct
Titusville, FL 32780
(407) 383-0410

Parent to Parent of Indian River
PO Box 6963
Vero Beach, FL 32961
(407) 770-0683

Family Network on Disabilities
PO Box 195747
Winter Springs, FL 32719
(407) 672-4707

Parent to Parent, Pasco Cty
PO Box 1533
Zephyrhills, FL 33539
(813) 783-8111

GEORGIA

Parent to Parent of Georgia
2900 Woodcock Blvd, Ste 240
Atlanta, GA 30341
(404) 451-5484

National Parent to Parent Support and Information System
PO Box 907
Blue Ridge, GA 30513
(706) 632-8822

HAWAII

Hawaii Down Syndrome Congress
419 Keoniana St, #804
Honolulu, HI 96815
(808) 949-1999

IDAHO

Parents Reaching Out to Parents
2195 Ironwood Ct
Coeurd'alene, ID 83814
(208) 769-1409

Idaho Autism Association
545 N 100 W
Jerome, ID 83338
(208) 324-2927

Parent to Parent
2714 8th Ave
Lewiston, ID 83501
(208) 746-8699

Palouse Area Parent to Parent, Whitman, Garfield & Asotin Ctys
103 S Polk
Moscow, ID 83843
(208) 882-9338

ILLINOIS

Archway Services for Children
1108 W Willow
Carbondale, IL 62959
(618) 549-4442

Developmental Services Center
1304 W Bradley
Champaign, IL 61821
(217) 359-0287

Illinois Next Steps, Parents Reaching Parents
100 W Randolph, Ste 8-100
Chicago, IL 60601
(800) 275-3677 (IL only)

Family Support Project
20 E Jackson Blvd, Rm 900
Chicago, IL 60604
(312) 939-3513

South Cook Cty Parent to Parent Program
Greater Interagency Council
800 Governor's Hwy
Flossmoor, IL 60422
(708) 957-7100

National Association for Down Syndrome
PO Box 4542
Oak Brook, IL 60522-4542
(708) 325-9112

INDIANA

First Step Early Intervention
PO Box 98
Batesville, IN 47006-0098
(812) 934-4528

Connection for Special Kids
692 ESR 218
Berne, IN 46711
(219) 589-3543

Down Syndrome Support Association
10792 Downing St
Carmel, IN 46033-3869
(317) 574-9757

Neo Fight
4363 Idlewild Ln
Carmel, IN 46033
(317) 843-0850

Abilities Services
PO Box 808
1237 Concord Rd
Crawfordsville, IN 47933
(317) 362-4020

Down Syndrome Association of NW Indiana
2927 Jewett Ave
Highland, IN 46322
(219) 836-3656

Indiana Parent Information Network
4755 Kingsway Dr
Indianapolis, IN 46205
(317) 257-8683

Special Education Parents Advisory Council
202 W 47th St
Indianapolis, IN 46208-3510
(317) 257-2962

First Steps
PO Box 6449
Lafayette, IN 47903-6449
(317) 423-5531

Roots-Wings Parent Involvement
1642 W McLain
Scottsburg, IN 47170
(812) 752-4892

Parent Family, Alumni Support
615 N Michigan St
South Bend, IN 46601
(219) 284-7308

Knox Cty Advocates for Special Kids
1806 Indiana Ave
Vincennes, IN 47591
(812) 882-0375

IOWA

Family Educator Connection Program
3706 Cedar Heights Dr
Cedar Falls, IA 50613
(319) 273-8265

Pilot Parents, The Arc of East Central Iowa
136 36th Dr SE, Ste A-5
Cedar Rapids, IA 52403
(319) 365-0487

Union Cty Pilot Parents
PO Box 57
Creston, IA 50801
(515) 782-5128

Autism Society of the Quad Cities
4712 Belle Ave
Davenport, IA 52807
(319) 359-5414

Parent-Educator Connection
MPRRC, Drake University
Des Moines, IA 50311
(515) 271-3936

Special Care Parents, Polk Cty
PO Box 938
Des Moines, IA 50304
(515) 279-7810

Iowa Pilot Parents
33 N 12th St, PO Box 1151
Fort Dodge, IA 50501
(515) 576-5870

PARENT TO PARENT PROGRAMS

Parent Educator Connection
1382 4th Ave NE
Sioux Center, IA 51250
(712) 722-4374

Parent to Parent Support Group
2320 S Olive
Sioux City, IA 51106
(712) 274-2838

KANSAS

Parent to Parent of Butler Cty
1432 W Olive
El Dorado, KS 67042
(316) 321-3274

Parent to Parent of Flint Hills
1722 Yucca Ln
Emporia, KS 66801
(316) 342-6954

Parent to Parent of Garden City
116 E Chestnut, Ste 103
Garden City, KS 67846
(316) 226-6364

Parent to Parent of NW Kansas
Box 15
Gem, KS 67734
(913) 462-6857

Parent to Parent, Wyandotte Cty
2234 Garfield Ave
Kansas City, KS 66104
(913) 342-9833

Parent to Parent, Douglas Cty
Rte 3, Box 56
Lawrence, KS 66044
(913) 832-1430

Parents Who Care
3312 Effingham
Manhattan, KS 66502
(913) 776-9268

Parent to Parent
30 Oak St Ct
Medicine Lodge, KS 67104
(316) 886-3590

Parent to Parent of NE Kansas
PO Box 488, 404 Pk
Oskaloosa, KS 66066
(913) 863-3257

Parent to Parent of SE Kansas
3118 Corning
Parsons, KS 67357
(316) 421-6550

Parent to Parent, Johnson Cty
10201 Horton
Shawnee Mission, KS 66207
(913) 967-7677

Rubinstein-Taybi Syndrome Parent Group
PO Box 146
Smith Center, KS 66967
(913) 697-2984

Families Together
501 Jackson St, Ste 400
Topeka, KS 66603
(913) 233-4777

Parent to Parent
2218 Wilmington Ct
Topeka, KS 66606
(913) 235-9680

Parent to Parent, Sedgwick Cty
2312 S Meridian, Ste 102
Wichita, KS 67213
(316) 945-7747

KENTUCKY

Parents Confronting Dual Sensory Impairments
PO Box 60
Fordsville, KY 42343
(502) 276-3360

Parents Outreach
1146 S Third St
Louisville, KY 40203
(502) 584-1239

Down Syndrome of Louisville
PO Box 22552
Louisville, KY 40252
(502) 425-0784

LOUISIANA

Parent Training Program
PO Box 94064
Baton Rouge, LA 70804
(504) 763-3588

Louisiana Rett Syndrome Foundation
7629 Sailfish Dr
Lake Charles, LA 70605
(318) 474-5727

Parent to Parent of Louisiana
Family Support Program
Children's Hospital
200 Henry Clay
New Orleans, LA 70118
(504) 896-9268

Concerned Parents For Students
1022 Gulf Ln
Sulphur, LA 70663
(318) 528 2191

MAINE

Maine Parent Federation
PO Box 2067
Augusta, ME 04338-2067
(207) 582 2504

Parent Program
11 Maple St
Rockland, ME 04841
(207) 594-8474

York Cty Parent Awareness
150 Main St, Midtown Mall
Sanford, ME 04073
(207) 324 2337

MARYLAND

Maryland Infants & Toddlers Program
1 Market Ctr, Ste 304
Baltimore, MD 21201-3446
(410) 333 8100

National Organization of Parents of Blind Children
1800 Johnson St
Baltimore, MD 21230
(410) 659-9314

Learning Disabilities Association of Metropolitan Baltimore
76 Cranbrook Rd, Ste 299
Cockeysville, MD 21030
(410) 821-7010

Epilepsy Foundation of America
4351 Garden City Dr
Landover, MD 20785
(301) 459-3700

MASSACHUSETTS

Greater Boston Parent to Parent
1505 Commonwealth Ave
Boston, MA 02135
(617) 783-3900

Birth Defects Service
Children's Hospital
300 Longwood Ave
Boston, MA 02115
(617) 735-6394

Parent Peer Support Group National Tay-Sachs & Allied Diseases Association
2001 Beacon St
Brookline, MA 02146
(617) 277-4463

Massachusetts Down Syndrome Congress
PO Box 866
Melrose, MA 02176
(617) 742-4440

Family Ties of Massachusetts
Dept of Public Health
180 Beaman St
West Boylston, MA 01583
(508) 792-7880

MICHIGAN

TRENDS
PO Box 1996
Holland, MI 49422-1996
(616) 392-6307

Kidpower
Autism Society of Michigan
809 Center St, Ste 8A
Lansing, MI 48904
(517) 487-9260

MINNESOTA

Pilot Parents of Northeastern Minnesota
201 Ordean Bldg
Duluth, MN 55802
(218) 726-4725

The Windmill Project
W Central ECSU
1001 E Mount Faith
Fergus Falls, MN 56537
(218) 739-3273

People To People Disability Aware
Rte 2, Box 145
Owatonna, MN 55060-9624
(507) 451-4585

Family Liason Project
903 W Center St, Rm 160
Rochester, MN 55902
(507) 287-2032

Midstate Pilot Parents
PO Box 1536
St Cloud, MN 56302
(612) 253-6844

Pilot Parents
425 Etna St, #35
St Paul, MN 55106
(612) 778-0727

Parents for Parents
280 N Smith Ave, Ste 245
St Paul, MN 55102
(612) 220-6731

Veteran Parents
280 N Smith Ave, Ste 245
St Paul, MN 55102
(612) 220-6731

MISSISSIPPI

Mississippi Gulf Coast Exceptional Parents
PO Box 271
Hurley, MS 39555
(601) 588-2260

MISSOURI

Parents Helping Parents
1702 E Laharpe
Kirksville, MO 63501
(800) 621-6082

Pilot Parents Program
PO Box 10984
Springfield, MO 65808-0984
(417) 831-0648

Positive Parenting Partners
United Services
4140 Old Mill Pkwy
St Peters, MO 63376
(314) 926-2700

PARENT TO PARENT PROGRAMS

Keeping Individuals With Developmental Disabilities Serviced
PO Box 1308
Warsaw, MO 65355
(816) 438-6990

MONTANA

Parents, Let's Unite For Kids
1500 N 30th St
Billings, MT 59101-0298
(406) 657-2055

Quality Life Concepts
600 6th St, NW
PO Box 2506
Great Falls, MT 59403
(406) 452-9531

Parents of Children With Special Needs
University of Montana
School of Education
Missoula, MT 59812
(406) 243-5344

NEBRASKA

Parent Assistance Network
310 W 24th
Kearney, NE 68847
(308) 237-6025

Parents Encouraging Parents
Nebraska Dept of Education
301 Centennial Mall S
Lincoln, NE 68509
(402) 471-2471

Pilot Parents Program
215 Centennial Mall S, #410
Lincoln, NE 68508
(402) 477-6925

Nebraska Family Support Network
215 Centennial Mall S
Lincoln, NE 68508
(402) 477-2992

Pilot Parents Program, Greater Omaha
3610 Dodge St
Omaha, NE 68131
(402) 346-5220

NEVADA

Nevada Association for the Handicapped
6200 W Oakey
Las Vegas, NV 89102
(702) 870-7050

Nevada Parent Network
College of Education/278
Reno, NV 89557-0082
(702) 784-4921

NEW HAMPSHIRE

Parent to Parent of Northern New Hampshire
69 Willard St
Berlin, NH 03570
(603) 752-8531

Upper Valley Support Group
PO Box 622
Hanover, NH 03755
(603) 448-6311

Parent to Parent of New Hampshire
PO Box 622
Hanover, NH 03755
(603) 448-6393

Parent to Parent
32 SW Hwy, Ste 22
Merrimack, NH 03054
(603) 882-6333

NEW JERSEY

Down Syndrome Parent to Parent
7 Regent St
Livingston, NJ 07039
(201) 535-1181

PEP: Parents Encouraging Parents
The Arc-Morris Chapter
PO Box 123
Morris Plains, NJ 07950
(201) 326-9750

Sturge-Weber Foundation
PO Box 418
Mt Freedom, NJ 07970
(201) 895-4445

National Urea Cycle Disorders Foundation
PO Box 32
Sayreville, NJ 08872
(800) 386-8233

Family Support Clearinghouse
2150 Hwy 35, Ste 207C
Sea Girt, NJ 08750
(908) 974-1144

NEW MEXICO

Parents Reaching Out
1127 University, NE
Albuquerque, NM 87102
(505) 842-9045

NEW YORK

Headway for Brain Injured
856 Ridge Rd
Buffalo, NY 14118
(716) 822-2261

Parent to Parent, Western NY
Parent Network of NY State
432 Delaware Ave
Buffalo, NY 14202
(800) 305-8813

Prader-Willi Forum
40 Holly Ln
Roslyn Heights, NY 11577
(800) 358-0682

Parents of Special Children
2C Tower Dr
Fulton, NY 13069
(315) 598-7672

The MPS Society
17 Kraemer St
Hicksville, NY 11801
(516) 931-6338

Parent to Parent, South Central NY
Family Resource Network
16 Ford Ave, Box 233
Oneonta, NY 13820
(800) 305-8814

Parent Assistance Committee on Down Syndrome
208 Lafayette Ave
Peekskill, NY 10566
(914) 739 4085

Parent to Parent of New York State
Balltown and Consaul Rds
Schenectady, NY 12304
(800) 305-8817

Parent to Parent, North Central NY
Exceptional Family Resources
731 James St, Ste 311
Syracuse, NY 13203
(800) 305-8815

Parent to Parent, Hudson Valley
Family Connection/WIHD
Cedarwood Hall
Valhalla, NY 10595
(800) 305-8816

Parent to Parent
239 Champion Ave
Webster, NY 14580
(716) 265-3778

NORTH CAROLINA

Parent to Parent
Rte 2, Box 178A
Angier, NC 27501
(919) 639-0172

Parents Reaching Out to Parents
PO Box 638
Biscoe, NC 27209
(910) 428-9944

Parent to Parent/Family Support
Appalachian State University
Edwin Duncan Hall
Boone, NC 28608
(704) 262-6089

Parent Support Group
63 N Canton Rd
Canton, NC 28716
(704) 452-4397

University Of North Carolina
School of Dentistry
Chapel Hill, NC 27599
(919) 966-2275

Family Support Network of North Carolina
UNC-Chapel Hill, CB#7340
Chapel Hill, NC 27599
(919) 966-2841

Family Support Network of Catawba Cty
Rte 2, Box 396
Conover, NC 28613
(707) 326-5953

Family Support Network of Orange, Durham & Chatham Ctys
115 Market St, Ste 201
Durham, NC 27701
(919) 560-5600

Family Support of the Albemarle Area
1601 Forest Dr
Elizabeth City, NC 27909
(919) 338-6987

Reaching Out Family Support Group
609-A Murchison Rd
Fayetteville, NC 28306
(910) 424-7669

Parent to Parent Support
Fort Bragg & Pope Families
8 Avellino Rd
Fort Bragg, NC 28307
(910) 960-2558

Family Support Network
1623 N Webb St School
Gastonia, NC 28054
(704) 854-4839

Family Support Network
719 E Ash St
Goldsboro, NC 27530
(919) 580-0330

Family Support Network of Greater Greensboro
801 Green Valley Rd
Greensboro, NC 27408
(910) 574-6507

Family Support Network of Eastern North Carolina
Irons Bldg, ECU Campus
Greenville, NC 27858
(919) 328-4494

Parents Resource Organization
142 Cemetery Rd
Mocksville, NC 27028
(910) 998-3311

Family Support Network/Hope Network
Western Carolina Ctr
300 Enola Rd
Morganton, NC 28655
(704) 433-2661

PARENT TO PARENT PROGRAMS

Family Support Network of the Neuse Area
1405 S Glenburnie Rd
New Bern, NC 28562
(919) 514-4770

Parents Encouraging Parents
PO Box 1318
Pisgah Forest, NC 27603
(704) 884-5649

Family Support Network, Wake Cty
319 Chapanoke Rd, Ste 101
Raleigh, NC 27603
(919) 662-4600

Child and Adolescent Network
4904 Watersedge Dr, Ste 152
Raleigh, NC 27606
(919) 851-0063

Child and Family Services Branch
Division of MH/DD/SAS
325 N Salisbury St, Rm 517
Raleigh, NC 27603
(919) 733-0598

Caring Parents
1506 Laurel St
Roanoke Rapids, NC 27870
(919) 535-5887

Family Support Network
Rt 11, Box 369A
Statesville, NC 28677
(704) 876-4621

Family Support Network of SE North Carolina
1804 Chestnut St
Wilmington, NC 28405
(910) 763-3331

Parents Together
4505 Shattalon Dr
Winston-Salem, NC 27106
(910) 924-5301

OHIO

Down Syndrome Association of Greater Cincinnati
1821 Summit Rd, Ste 102
Cincinnati, OH 45237
(513) 761-5400

Ohio Protection & Advocacy Association
4030 Mt Carmel/Tobasco, Ste 214
Cincinnati, OH 45255
(513) 528-4690

Ohio Protection & Advocacy Association
5030 Brookpark Rd
Cleveland, OH 44134
(216) 398-5501

The Family Information Network
246 N High St, 5th Fl
Columbus, OH 43266
(614) 644-8389

Ohio Head Injury Association
1335 Dublin Rd, Ste 50A
Columbus, OH 43215
(614) 481-7100

Celebrating Families of Children
16 Vassar Dr
Dayton, OH 45406
(513) 275-0990

Special Needs Information Center
832 Shannon Rd
Girard, OH 44420
(216) 545-2837

Miami Valley Down Syndrome Association
1444 Beaver Creek Ln
Kettering, OH 45429
(513) 294-1240

Family Information Network of NW Ohio
1 Stranahan Sq, #540
Toledo, OH 43604
(419) 242-9587

OREGON

The Arc of Lane Cty
Parent Network
45 W Broadway, Ste 205
Eugene, OR 97401
(503) 343-5256

Parent Support Group
2825 Barnett Rd
Medford, OR 97504
(503) 770-4233

Oregon Cope Project
999 Locust St NE
Salem, OR 97303-5299
(503) 373-7477

PENNSYLVANIA

Brain Injury Support Group
595 W State St
Doylestown, PA 18901
(215) 345-2634

Parent Support Center
252 Waterford St
Edinboro, PA 16412
(814) 734-5610

Westmoreland Cty Parent to Parent
Rd 12 Box 179
Donohoe Rd
Greensburg, PA 15601
(412) 837-8159

Down Syndrome Support Group of Lancaster Cty
c/o S. June Smith Ctr
25 NW End Ave
Lancaster, PA 17603
(717) 299-4829

Charcot-Marie-Tooth Association
601 Upland Ave
Upland, PA 19015
(800) 606-2682

RHODE ISLAND

Parents Reaching Out
1 Simmons Rd
Barrington, RI 02806
(401) 245-5241

Down Syndrome Society of Rhode Island
99 Bald Hill Rd
Cranston, RI 02920
(401) 463-5751

Parent Training Program, Special Education
22 Hayes St
Providence, RI 02908
(401) 277-3505

Central Region Early Intervention Program
J Arthur Mem Ctr
250 Commonwealth
Warwick, RI 02886
(401) 823-1731

SOUTH CAROLINA

Family Connection of South Carolina
2712 Middleburg Dr
Columbia, SC 29204
(803) 252-0914

Parents Reaching Out, Parents of South Carolina
2712 Middleburg Dr, Ste 102
Columbia, SC 29204
(803) 779-3859

SOUTH DAKOTA

Parent to Parent
2501 W 26th St
Sioux Falls, SD 57105-2498
(605) 334-3119

TENNESSEE

Parent to Parent
312 8th Ave, 10th Fl
Nashville, TN 37247
(615) 741-0361

TEXAS

Parent Case Management Program
4601 Hartford
Abilene, TX 79605
(915) 691-7232

Pilot Parent
The Arc
2818 San Gabriel
Austin, TX 78705-3598
(512) 476-7044

Partners Resource Network
1090 Longfellow, Ste B
Beaumont, TX 77706-4889
(409) 898-4684

Parent to Parent
PO Box 113162
Carrollton, TX 75011-3163
(214) 994-3484

Tarrant Cty Society for Hearing Impaired Infants and Youth
6416 Canyon Cir
Fort Worth, TX 76133
(817) 346-0421

Parent to Parent
307 Peterson
Royse City, TX 75089
(214) 636-9604

Parent Case Management Program of West Texas Rehabilitation Centers
3001 S Jackson
San Angelo, TX 76904
(915) 949-9535

UTAH

Parent to Parent
50 N Medical Dr, Rm 2553
Salt Lake City, UT 84132
(801) 581-2098

Graduate Parents
100 N Medical Dr
Salt Lake City, UT 84113-1100
(801) 588-3899

HOPE: A Parent to Parent Network
2290 E 4500 S, Ste 110
Salt Lake City, UT 84117
(801) 272-1051

VERMONT

Vermont Family Resource Consultants
UAP of Vermont
499C Waterman Bldg
Burlington, VT 05405
(802) 656-4031

Parent to Parent of Vermont
1 Main St, 69 Champlain Mill
Winooski, VT 05404
(802) 655-5290

VIRGINIA

Culpepper Area Parent to Parent
Rte 2, Box 263J
Amissville, VA 22002
(703) 937-2155

Parent to Parent of Alexandria
4729 N 20th St
Arlington, VA 22207
(703) 524-8222

SW Virginia Parent to Parent
Drawer II
Big Stone Gap, VA 24219
(703) 523-0682

PARENT TO PARENT PROGRAMS

Craniofacial Anomalies Clinic
Box 376
Charlottesville, VA 22908
(804) 924-5801

Charlottesville Parent to Parent
Rte 2, Box 402A
Crozet, VA 23932
(804) 973-2247

Prince William Parent to Parent
15077 Lindenberry Ln
Dumfries, VA 22026
(703) 691-7826

Parent to Parent of Northern Virginia
PEATC
10340 Democracy Ln, Ste 206
Fairfax, VA 22030
(703) 691-7826

Parent to Parent of Hampton Roads
16008 5th St
Bethel Manor
Hampton, VA 23655
(804) 865-0463

Harrisonburg-Rockingham Parent to Parent
1251 Smithland Rd
Harrisonburg, VA 22801
(703) 433-5821

Twin Cty/Galax Parent to Parent
PO Box 931
Hillsville, VA 24343
(703) 236-6585

Parent to Parent, Whythe Cty
Rte 1, Box 50
Ivanhoe, VA 24350
(703) 699-6341

Parent to Parent of Central Virginia
Arc of Central Virginia
1264 Krise Cir
Lynchburg, VA 24503

Fairfax Cty Parent to Parent
10509 Adel Rd
Oakton, VA 22124
(703) 281-7113

Parent to Parent of Southside Virginia
20 W Bank St, Ste C
Petersburg, VA 23803
(804) 862-8049

Parent to Parent of Southside Virginia
Crater District Infant Intervention Program
2008 Wakefield Ave
Petersburg, VA 23805
(804) 862-9940

Parent to Parent
1518 Willow Lawn Dr
Richmond, VA 23230
(804) 282-4255

Richmond Parent to Parent
1540 Honey Grove Dr
Richmond, VA 23229
(804) 270-1883

Parent to Parent of Roanoke
3857 Hummingbird Ln
Roanoke, VA 24018
(703) 989-5042

Parent to Parent, Roanoke
3020 Mansfield St
Roanoke, VA 24012
(703) 366-3551

Parents of Children with Down Syndrome
6111 Roxbury Ave
Springfield, VA 22152
(703) 451-6328

Raddanock Parent to Parent
2015 Buoy Dr
Stafford, VA 22554
(703) 659-4957

Loudon Parent to Parent
104 Country Rd
Sterling, VA 20165
(703) 406-7804

Tidewater Area Parent to Parent
707 Gittings St, Ste 170
Suffolk, VA 23434
(804) 539-8616

Virginia Beach Parent to Parent
405 W Farmington Rd
Virginia Beach, VA 23454
(804) 340-1954

WASHINGTON

Grays Harbor Parent to Parent
117 E 3rd, PO Box 1827
Aberdeen, WA 98520
(206) 533-5100

Parent to Parent, Whatcom Cty
1111 Cornwall Ave, Ste 205
Bellingham, WA 98225
(206) 966-7932

Parent to Parent
The Arc of Kitsap Cty
3243 N Perry Ave
Bremerton, WA 98310
(206) 377-3473

Parent to Parent Support Program
156 NW Prindle
Chehalis, WA 98532
(206) 748-4359

Parent to Parent, Snohomish Cty
2531 Wetmore
Everett, WA 98201-2919
(206) 258-2459

Parent to Parent Support Program
The Arc of Cowlitz Valley
1129 Broadway
Longview, WA 98632
(206) 532-5494

Parent to Parent, Grant, Adams & Lincoln Ctys
903 W 3rd
Moses Lake, WA 98837
(509) 765-3686

Parent to Parent Support Program, Skagit Cty
PO Box 1833
Mount Vernon, WA 98273
(206) 757-7048

Parent to Parent, Thurston Cty
1703 E State Ave
Olympia, WA 98506
(206) 352-1126

Parent to Parent
PO Box 3051
Omak, WA 98841
(509) 826-0716

Parent to Parent Support Program, Clallam Cty
2039 W 10th St
Port Angeles, WA 98363
(206) 457-1282

Parent to Parent Support Program, Benton & Franklin Ctys
767 Williams Blvd
Richland, WA 99352
(509) 943-2908

The Cleft Connection
110 Prefontaine Pl S, Ste 500
Seattle, WA 98104
(206) 296-4665

Parent to Parent Programs
The Arc of King Cty
10550 Lake City Way NE, Ste A
Seattle, WA 98125-7752
(206) 948-7322

King Cty Parent to Parent
10550 Lake City Wy NE, Ste A
Seattle, WA 98125-7752
(206) 364-4645

Parent to Parent Support Programs, Mason Cty
428 W Birch
Shelton, WA 98584
(206) 426-1005

Parent to Parent Support Program, Spokane Cty
W 127 Boone Ave
Spokane, WA 99201
(509) 244-4499

Parent to Parent
12208 Pacific Hwy SW
Tacoma, WA 98499
(206) 588-1741

Parent to Parent Support Program
Arc of Clark Cty
PO Box 2608
Vancouver, WA 98668
(206) 254-1562

Parent to Parent/De Padre a Padre, Walla Walla & Columbia Ctys
PO Box 1595
Walla Walla, WA 99362
(509) 527-3278

Parent to Parent, Chelan & Douglas Ctys
PO Box 1
Wenatchee, WA 98807
(509) 782-4476

Parent to Parent Support Program
603 S 18th Ave
Yakima, WA 98902
(509) 452-1382

WEST VIRGINIA

Autism Services Center
Prichard Bldg, 9th Fl
605 9th St
Huntington, WV 25710-0507
(304) 525-8014

WISCONSIN

Pilot Parents
Rte 2, Box 434
Ashland, WI 54806
(715) 682-2671

Brown Cty Arc
PO Box 12770
Green Bay, WI 54307-2770
(414) 498-2599

DEAF
PO Box 23825
Green Bay, WI 54305-5825
(414) 437-7531

MUMS National Parent to Parent
150 Custer Ct
Green Bay, WI 54301-1243
(414) 336-5333

SW Wisconsin Parents of Down Syndrome Persons
18716 W Mound Rd
Platteville, WI 53818
(608) 348-8906

Racine Parent Support
The Arc
818 6th St
Racine, WI 53403
(414) 634-6303

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☐ Camerer, M. C. & Emerson Capps—**RAISING OTHER PEOPLE'S KIDS: A Guide for Houseparents, Foster Parents, and Direct Care Staff.** '95, 188 pp. (7 × 10).

☐ Morton-Young, Tommie—**AFTER-SCHOOL AND PARENT EDUCATION PROGRAMS FOR AT-RISK YOUTH AND THEIR FAMILIES: A Guide to Organizing and Operating a Community-Based Center for Basic Educational Skills Reinforcement, Homework Assistance, Cultural Enrichment, and a Parent Involvement Focus.** '95, 148 pp. (7 × 10), 1 il. Cloth—$37.95, paper—$22.95.

☐ Holley, Shelby—**A PRACTICAL PARENT'S HANDBOOK ON TEACHING CHILDREN WITH LEARNING DISABILITIES.** '94, 308 pp., 13 il., 1 table, $61.95. *$34.95, paper.*

☐ Anderson, Frances E.—**ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES.** '94, 284 pp. (6¾ × 9¾), 100 il., 14 tables, $44.95. *$29.95, paper.*

☐ Kass, Corrine E. & Cleborne D. Maddux—**A HUMAN DEVELOPMENT VIEW OF LEARNING DISABILITIES: From Theory to Practice.** '93, 222 pp. (7 × 10), 3 il., $47.95. *$29.95, paper.*

☐ Girodano, Gerard—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 × 10), 85 il., 26 tables, $59.95. *paper.*

☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 × 10), 32 il., 8 tables, $75.95. *$39.95, paper.*

☐ Jones, Carroll J.—**CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS.** '93, 174 pp. (7 × 10), $38.95. *$24.95, paper.*

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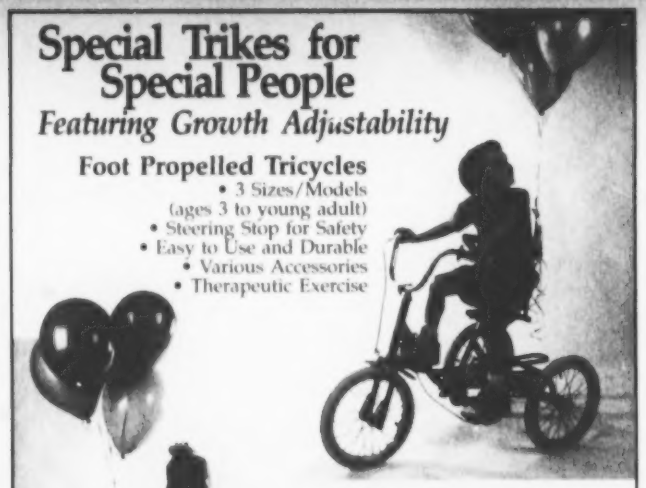

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A description of services provided by individual centers follows each listing. Numbers correspond to items listed in the Key to Services.

This symbol (📧) indicates an Internet e-mail address.

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Birmingham Independent Living Ctr
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Birmingham, AL 35233-1317
(205) 251-2223 (V/TTY)
(205) 251-0605 (fax)
1,2,3,4,5,6,8,11,13,14,16,19,20; Braille services, home visits

Technology Assistance for Special Consumers
PO Box 443
Huntsville, AL 35804
(205) 532-5996 (V/TTY)
(205) 532-5994 (fax)
📧 tascal@aol.com
1,2,3,4,5,6,7,8,9,10,11,12,13,14,15,19,20

ALASKA

Alaska Services For Enabling Technology
207 Moller Dr, PO Box 6485
Sitka, AK 99835
(907) 747-7615 (voice)
📧 asetseak@aol.com
1,2,5,6,8,19; expertise in technology for people with vision impairments

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Technology Access Center of Tucson
4710 E 29th St
PO Box 13178
Tucson, AZ 85732-3178
(602) 745-5588 (voice)
📧 tactaz@aol.com
1,2,7,8,9,10,11,12,13,14,15,19,20; disability awareness sessions

ARKANSAS

Technology Resource Center
c/o Arkansas Easter Seal Society
3920 Woodland Heights Rd
Little Rock, AR 72212-2495
(501) 227-3600 (voice)
(501) 227-3601 (fax)
📧 atrce@aol.com
1,2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20; District Assistive Technology Service Plan

CALIFORNIA

Center for Accessible Technology
2547 8th St, 12-A
Berkeley, CA 94710-2572
(510) 841-3224 (V/TTY)
(510) 841-7956 (fax)
📧 cforat@aol.com
1,2,3,4,5,6,7,9,10,11,12,13,14,15,16,17,19,20

Computer Access Center
1807 Wilshire Blvd, #202
Santa Monica, CA 90403
(310) 829-6395 (voice)
📧 cacofsmca@aol.com
1,2,4,5,6,7,8,9,11,12,13,15,16,17,19,20

Sacramento Center for Assistive Technology
4370 Mather School Rd
Mather, CA 95655
(916) 361-0553 (V/TTY)
(916) 361-0554 (fax)
📧 scat1@aol.com
1,2,3,6,9,11,12,15,19,20

Special Awareness Computer Center
Rehabilitation Unit North
2975 N Sycamore Dr
Simi Valley, CA 93065
(805) 582-1881 (voice)
(805) 582-2855 (fax)
📧 sacca@aol.com
1,2,12,13,15

Special Technology Center
590 Castro St
Mountain View, CA 94041
(415) 961-6789 (voice)
(415) 961-6775 (fax)
1,2,6,8,9,10,11,12,13,15,16,20

Team of Advocates for Special Kids
100 W Cerritos Ave
Anaheim, CA 92805-6546
(714) 533-8275 (voice)
(714) 533-2533 (fax)
📧 taskca@aol.com
1,2,5,6,7,8,12,13,14,15,16,18,20; consultations, Saturday open labs

FLORIDA

Center for Independence Technology and Education
215 E New Hampshire St
Orlando, FL 32804
(407) 898-2483 (voice)
(407) 895-5255 (fax)
📧 cite@applelink.apple.com
1,2,3,4,5,7,8,9,10,11,12,13,14,15,16,17,18,19,20, parent support group

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9. Videotape lending library
10. Constructing/adapting switches and devices
11. Technical assistance to IEP teams
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13. Parent/family training
14. Augmentative communication training
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HAWAII

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Honolulu, HI 96826-3725
(808) 955-4464 (voice/fax)
📧 stachi@aol.com
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ILLINOIS

Northern Illinois Center for Adaptive Technology
3615 Louisiana Rd
Rockford, IL 61108-6195
(815) 229-2163 (voice)
(815) 229-2120 (fax)
📧 ilca@aol.com
1,2,3,4,5,6,7,8,9,10,11,12,13,15,17,18,19,20

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(312) 421-3373 (V/TTY)
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INDIANA

Assistive Technology Training and Information Center
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Vincennes, IN 47591
(800) 962-8842 (V/TTY)
(812) 882-1128 (fax)
inattic1@aol.com
1,2,4,5,6,7,8,9,10,11,12,13,15, 18,19

KANSAS

Technology Resources and Solutions for People
3023 Canterbury Rd
and 1710 W Schilling Rd
Salina, KS 67401
(913) 827-9383 (V/TTY)
(913) 827-0301 (V/TTY)
(913) 827-5446 (fax)
trspks@aol.com
1,4,5,7,8,11,12,13,14,15,16,18

KENTUCKY

Blue Grass Technology Center
169 N Limestone
Lexington, KY 40507
(606) 255-9951 (V/TTY)
(606) 255-0059 (fax)
bluegrass@aol.com
1,2,3,4,6,7,8,9,10,11,12,14,15, 18,19; supported employment services for rural Kentucky

Enabling Technologies of Kentuckiana
Louisville Free Public Library
301 York St
Louisville, KY 40203-2257
(502) 574-1637 (voice)
(502) 574-1674 (TTY)
(502) 582-2448 (fax)
entecky@aol.com
1,2,3,6,7,8,9,11,12,13,14,15,16, 17,18,19,20

SpeciaLink
36 W 5th St
Covington, KY 41011
(606) 491-2464 (voice/fax)
splinkky@aol.com
1,2,3,4,5,6,7,8,9,10,11,12,13, 14,15,16,19,20; software development; regional center for SW Ohio, N Kentucky & SE Indiana

LOUISIANA

CATER-Center for Adaptive Technology and Educational Resources
731 Park Ave
Mandeville, LA 70448-4918
(504) 626-7088 (voice/fax)
caterla@aol.com
1,2,4,5,7,9,10,11,12,13,15,18,20

MARYLAND

Learning Independence Through Computers
28 E Ostend St
Baltimore, MD 21230
(410) 659-5462 (voice)
(410) 659-5469 (TTY)
(410) 659-5472 (fax)
lincmd@aol.com
1,2,5,10,12,13,15,17,19,20

MASSACHUSETTS

Massachusetts Special Technology Access Center
12 Mudge Way 1-6
Bedford, MA 01730-2138
(617) 275-2446 (voice)
1,2,5,7,8,9,10,11,12,13,14,15, 16,19,20

MICHIGAN

Living & Learning Resource Centre
Physically Impaired Association of Michigan
601 W Maple St
Lansing, MI 48906-5038
(517) 487-0883 (V/TTY)
(517) 487-1605 (fax)
llrcmi@aol.com
1,2,3,5,6,8,9,11,12,13,14,15,19

MINNESOTA

PACER Computer Resource Center
4826 Chicago Ave S
Minneapolis, MN 55417-1098
(612) 827-2966 (V/TTY)
(612) 827-3065 (fax)
lina100w@wonder.em.cdc.gov
1,3,4,5,6,8,9,11,12,13,15,20

MISSOURI

Technology Access Center
12110 Clayton Rd
St Louis, MO 63131-2599
(314) 569-8404 (voice)
(314) 569-8400 (TTY)
(314) 993-5937 (fax)
mosttac@aol.com
1,4,5,6,9,12,13,15,19,20

MONTANA

Parents, Let's Unite for Kids
MSU Billings SPED267
1500 N 30th St
Billings, MT 59101-0296
(406) 657-2055 (V/TTY)
(406) 657-2061 (fax)
plukmt@aol.com
1,2,3,4,5,6,7,8,9,10,11,12,13, 15,16,17,18,19,20; book-lending library, MedLine searches, database, Parent Training Center

NEW JERSEY

Center for Enabling Technology
622 Route 10 W, #22B
Whippany, NJ 07981-0272
(201) 428-1455 (voice)
cetnj@aol.com
1,2,3,12,13,15,16,17,20; open resource times

Computer Center for People with disAbilities
35 Haddon Ave
Shrewsbury, NJ 07702-4007
(908) 747-5310 (voice)
(908) 747-5936 (fax)
ccdanj@aol.com
1,2,5,6,7,9,10,12,13,14,15,16, 17,20; specialty groups: ADD club, Kids Helping Kids, Creative Writing

NEW YORK

Techspress
Resource Ctr for Independent Living
409 Columbia St
Utica, NY 13502-0210
(315) 797-4642 (voice)
(315) 797-5837 (TTY)
(315) 797-4747 (fax)
bprsny@aol.com
1,2,3,6,7,8,10,11,12,13,14,15, 18,19,20

NORTH CAROLINA

Carolina Computer Access Center
700 East Second St
Charlotte, NC 28202-2826
(704) 342-3004 (voice/fax)
ccacnc@aol.com
1,2,4,5,6,8,9,10,12,15,16,19,20

NORTH DAKOTA

Pathfinder Services of North Dakota
1600 2nd Ave SW
Minot, ND 58701
(701) 852-9426 (voice)
(701) 838-9324 (fax)
pathfinder@aol.com
1,5,7,9,11,12,13,14,15,16,18,20

Key to Services

1. Hands-on computer demonstrations
2. Guided exploration and problem-solving
3. Formal technology-needs assessments
4. Assistance in obtaining assistive technology funding
5. Software lending library
6. Loans of computers and hardware
7. Toy lending library
8. Loans of assistive devices
9. Videotape lending library
10. Constructing/adapting switches and devices
11. Technical assistance to IEP teams
12. Teacher training
13. Parent/family training
14. Augmentative communication training
15. Workshops
16. Early childhood/preschool programs
17. Computer camps/After-school programs
18. Transition training for young adults
19. Technical assistance to employers
20. Newsletter

OHIO

Technology Resource Center
301 Valley St
Dayton, OH 45404-1840
(513) 222-5222 (voice)
(513) 222-2101 (fax)
trcdoh@aol.com
1,2,4,5,6,7,8,9,10,11,12,13,14, 15,16,17,18,19,20

RHODE ISLAND

TechACCESS Center of Rhode Island
300 Richmond St
Providence, RI 02903-4222
(401) 273-1990 (V/TTY)
(401) 831-1131 (fax)
accessri@aol.com
1,2,11,12,13,14,15,16,17,20

TENNESSEE

East Tennessee Special Technology Access Center
3525 Emory Rd NW
Powell, TN 37849
(615) 947-2191 (voice)
(615) 947-2194 (fax)
etstactn@aol.com
1,2,3,4,5,6,7,8,9,10,11,12,13, 15,16,17,19,20

Emily Landau, 3, travels everywhere with her best friend, "Puffy," safely ensconced in the basket of her walker. Emily, who has Larsen syndrome and cervical kyphosis, is described by her mother as "bright, inquisitive and talkative." She lives in West Babylon, New York.

Technology Access Center of Middle Tennessee
2222 Metro Center Blvd. #126
Nashville, TN 37228
(615) 248-6733 (V/TTY)
(615) 259-2536 (fax)
tactn@aol.com
1,2,3,4,5,6,8,9,11,12,13,14,15, 19,20

West Tennessee Special Technology Access Resource Center
60 Lynoak Cove
Jackson, TN 38305
(901) 668-3888 (voice)
(901) 668-1666 (fax)
startn@aol.com
1,2,3,4,5,6,7,8,10,12,13,14,15, 16,17,18,19,20

UTAH

Computer Center for Citizens with Disabilities
2056 S 1100 E
Salt Lake City, UT 84106
(801) 485-9152 (V/TTY)
(801) 485-8675 (fax)
ccdut@aol.com
1,2,8,9,12,14,15,20

VIRGIN ISLANDS

Virgin Islands Resource Center for the Disabled
74-B & 75 Kronprindsen Gade
Box 1825
St. Thomas, USVI 00803
(809) 777-2253 (voice)
(809) 774-5816 (fax)
1,3,4,7,9,11,12,13,14,15,16,17, 18,19,20

VIRGINIA

Tidewater Center for Technology Access
Special Education Annex
Celebration Station
3352 Virginia Beach Blvd. #112
Virginia Beach, VA 23452
(804) 431-4095 (V/TTY)
(804) 431-4089 (fax)
tcta@aol.com
1,2,3,4,5,8,9,10,11,12,14,15,16, 17

WEST VIRGINIA

Eastern Panhandle Technology Access Center
110 Mordington, PO Box 987
Charles Town, WV 25414
(304) 725-6473 (V/TTY/fax)
eptac@aol.com
1,2,4,5,6,7,8,9,10,11,12,13,15, 16,17,18,19,20

Project GLUE
South Charleston Public Library
312 4th Ave
S Charleston, WV 25303
(304) 342-6501 (V/TTY)
glueata@aol.com
1,2,12,13,15

CANADA

Alliance Centre for Technology
360 George St N #202
Peterborough, Ontario K9J7E7
(705) 741-4214 (V/TTY)
(705) 741-4581 (fax)
alliance@trentu.ca
1,2,3,4,10,12,13,14,15,19,20

Make your child a star in my **CooperCar!**

New and improved!
1) More power
2) Proportional joystick
3) More speeds

Still...

Adaptable to any child, any switch and...

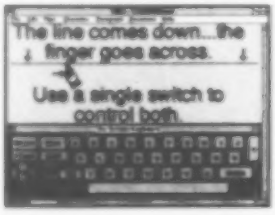
...less than $1000!

BEWARE! You may see ads with products that look like mine, but they are simply more expensive

Hi!

I'm RJ Cooper, inventor of the CooperCar, SAM, and many special needs computer programs for your child. I've been helping parents and professionals for 10 years now, and I'm here to help **you!**

When you call me, I'll share with you my experiences, methods, and materials that have helped thousands of children become successful, many for the first time in their lives!



CrossScanner

...lets one switch (or any pointing device) do *everything* on your Mac or Windows computer!

SAM

...my Switch-Adapted Mouse device...

...lets you plug switches into your computer!

I also make a variety of special needs software for your Mac, Windows, or Apple II computer.

So, for a free catalog or advice, call me, *RJ*, at...

1-800-RJCooper

RJ Cooper & Associates
24843 Del Prado #283 Dana PT, CA 92629
Voice: 714-240-4853 Fax: 714-240-9785
Email: rjcoop@aol.com

Circle # 80

Special Auto Insurance for Special People

OUR **ABILITIES PLUS**™ PROGRAM IS DESIGNED TO ADDRESS THE SPECIAL NEEDS OF PARENTS OF CHILDREN WITH DISABILITIES BY PROVIDING EXPANDED AUTO INSURANCE BENEFITS FOR MODIFIED VEHICLES, AND VALUE-ADDED SERVICES.

CUSTOMIZED COVERAGE; FAST, FAIR CLAIM HANDLING; AND CUSTOMER SERVICE 24 HOURS A DAY, EVERY DAY OF THE YEAR.

FOR ADDITIONAL INFORMATION, INCLUDING A QUOTE, CALL 1-800-222-2788

ASK FOR DEPARTMENT P

P.O. Box 51198, Lutherville, MD 21094-9719

The Maryland
Personal Insurance

COVERAGE AVAILABILITY VARIES BY STATE

Circle # 131

FREE SAMPLES

Save up to 60% on Disposable Diapers
And We Will Deliver Right to Your Door

To order, call toll-free

1-800-777-1111

24 Hour Service

Ask about our complete catalog including Depend, Attends, At Ease, Comfort Dry, Ultra Shield, Dri Pride, Promise and No-Rinse Products

Woodbury Products, Inc.

4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle # 72

TIRED OF YOUR BATTERIES NOT PERFORMING?

INCREASE YOUR BATTERY LIFE 2–3 TIMES!

A new innovation made possible by microelectronics puts a battery management system at your finger tips.

Never charge your battery again, unless you want to replace it before its time, and worry yourself silly in the process. Tend your batteries with the amazing new ***InteliTender***.

We carry a full line of replacement batteries and battery tenders for motorized wheelchairs, scooters and tri-carts.

For further information call:

1-800-572-4888 ext.113

PBS
PRO BATTERY SPECIALISTS
MANUFACTURING AND SALES

890 W. 23rd ST. ▪ HIALEAH, FL 33010

Circle # 49

WILLOW RIVER FARMS

An active organic farming and artisan community meeting the special needs of men and women with mental retardation.

At Willow River we offer...

- ❒ A family-based home environment that incorporates traditional values
- ❒ A setting that fosters personal growth, independence, and self respect
- ❒ Opportunities for productive work through individualized programming
- ❒ A home for persons age 21 and older

Contact:
Jimmy R. Haskins, Ed.D., Director
Willow River Farms
P.O. Box 450
San Felipe, TX 77473

WILLOW RIVER FARMS

Operated by:
Center for the Retarded, Inc. (CRI)
Houston, TX
B.R. (Bill) Walker, Ph.D.
Executive Director

CALL (409) 885-4121

~~$5~~

Circle # 91

PRODUCT NEWS

Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.

Full Range of Accessories

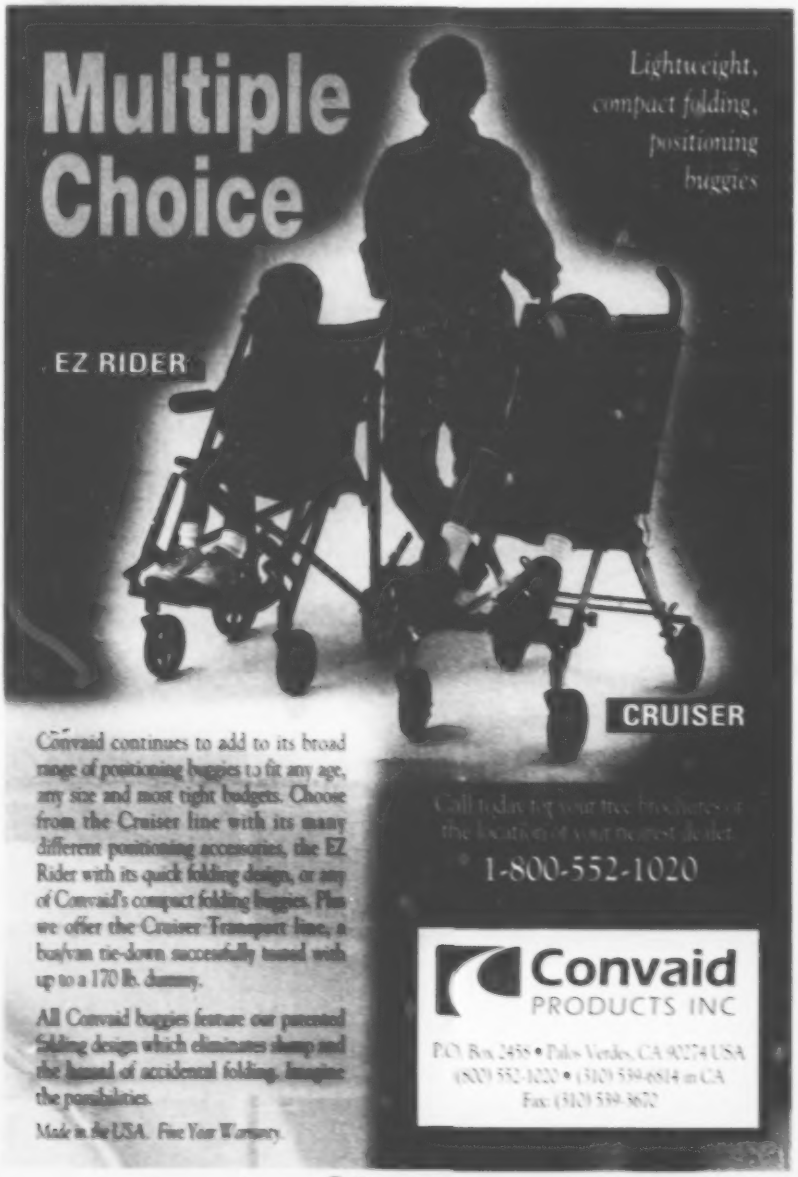
A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.

New Bus/Van Tie-Down Models

Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.

Good Looks, and Custom Comfort Make Kids Smile

Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability.


Multiple Choice
Lightweight, compact folding, positioning buggies
EZ RIDER
CRUISER
Convaid continues to add to its broad range of positioning buggies to fit any age, any size and most tight budgets. Choose from the Cruiser line with its many different positioning accessories, the EZ Rider with its quick folding design, or any of Convaid's compact folding buggies. Plus we offer the Cruiser Transport line, a bus/van tie-down successfully tested with up to a 170 lb. dummy.
All Convaid buggies feature our patented folding design which eliminates slump and the hazard of accidental folding. Imagine the possibilities.
Made in the USA. Five Year Warranty.
Call today for your free brochure or the location of your nearest dealer
1-800-552-1020
Convaid
PRODUCTS INC
P.O. Box 2458 • Palos Verdes, CA 90274 USA
(800) 552-1020 • (310) 539-6814 in CA
Fax (310) 539-3672

Helping Children Shape Their Lives

Our caring staff is committed to helping children shape their lives through personal choice and a solid foundation of learning.

Specialized education and therapy programs are tailored to meet your child's needs.

Working together, we can help them reach their goals.

. . . Right From The Start

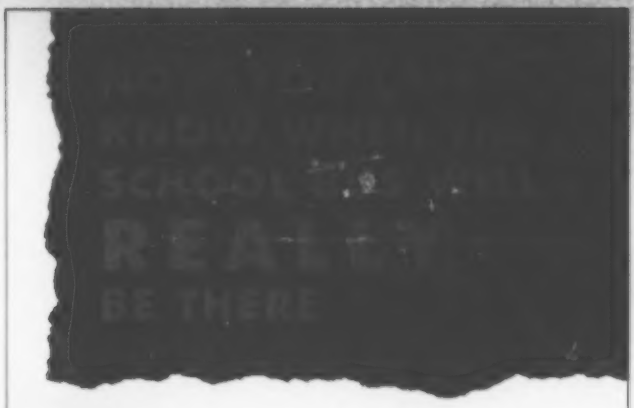
Elwyn Inc. day and residential programs, include:

- early intervention
- pre-school for disabled and non-disabled children together
- elementary and secondary education
- post-graduation transitional services
- vocational training and placement
- award-winning therapeutic recreation facilities
- 24-hour health care services
- modern, home-like residential settings

Elwyn, caring for over 10,000 children and adults with varying disabilities, has locations throughout Pennsylvania, New Jersey, Delaware, California, and Jerusalem.

ELWYN INC. • Admissions Office
111 Elwyn Road • Elwyn, PA 19063-4699
(610) 891-2256 (PA) • (800) 345-8111 (outside PA)

Circle # 79



Bustop Alert

is a state-of-the-art electronics school bus to home alerting system that:

- **gives parents that precious extra time to prepare their children**
- **gives children the safety and comfort of waiting inside – not outdoors in bad weather**
- **gives children who are wheelchair-bound or use other adaptive devices a needed advantage**
- **gives children the comfort of less time spent on the bus riding to and from school.**

"Here Comes The Bus"™

For more information about this unique system, call:

1-800-370-6406

BUSTOP ALERT

254 Charlevoix
Grosse Pointe Farms
Michigan 48236
FAX: (313) 885-7075

87

Circle # 50

KALEIDOSCOPE
Television is important for America's disability community. The network's programming helps Americans with disabilities move into mainstream life by changing perceptions.

SENATOR BOB DOLE

KALEIDOSCOPE not only gives people with disabilities a new means of communication, but television gives all Americans an opportunity to maximize abilities.

SENATOR TOM HARKIN

As one of 49 million Americans who happens to have a disability, like I happen to have epilepsy, I'm very excited about KALEIDOSCOPE. KTV uses the extraordinary power of television to communicate ideas and positive role models for our complex society.

TONY COELHO, Chairman
President's Committee
on Employment of People
with Disabilities

Please join March of Dimes and KALEIDOSCOPE. With your help, we can improve the quality of life for Americans with birth defects and other disabilities. And we can offer quality programming the whole family can enjoy.

DR. JENNIFER L. HOWSE
President
March of Dimes
Birth Defects Foundation

Join with us at Easter Seals and KALEIDOSCOPE. We want to share vital, accurate information. We want to brighten American homes from coast to coast with good, quality television.

JAMES E. WILLIAMS, JR.
President and CEO
National Easter Seal Society

We're delighted to join KALEIDOSCOPE in the "Calling on Cable" campaign. I hope you will become a part of the effort to bring this exciting network to every home in America.

ELAINE L. CHAO
President and CEO
United Way of America

KTV

AMERICA'S DISABILITY CHANNEL

Now DigiVox Gives You Even *More* Value.

Many of you have told us how pleased you are with all the portable power you've found in the DigiVox® augmentative communication aid. In fact, some of you feel it offers such an extraordinary value that you've asked for even *more* of a good thing.

Announcing 8 Full Levels. In response to your requests, we've *doubled* the DigiVox's original 4 memory levels, to give you *8 full levels* with up to 48 addressable message-areas on each. That means you can now provide a user with as many as 384 single-access messages. And if you want, just think what you can do with sequencing.

Superior Sound Quality. DigiVox's advanced digital technology lets you make high-quality recordings and play them back in the clearest, most natural-sounding speech available on a communication aid.

Easier Programming. With DigiVox, you have a built-in electronic display window that gives you step-by-step instructions, and guides you through the programming process. This reduces the need to memorize program codes.

Your Own Message Library. DigiVox gives you all the built-in message time you need (up to 35 minutes, fully extended model). But it doesn't stop there. It also lets you save an ***unlimited*** number of additional messages, simply by copying them to a floppy disk. And you don't have to buy a computer system to do it – just an inexpensive DigiVox disk drive.

Personal Support. Plus, when you purchase a DigiVox, you get personal training *and* direct access to our experienced Customer Support staff to answer any question you might have.

Unequalled Value. You'll find DigiVox gives you more built-in capabilities and standard accessories (such as overlays, shoulder strap, and 3 access methods) than any other digitized aid. And it's surprisingly affordable, too. So, when you compare feature for feature, we think you'll agree DigiVox is an unequalled communication value.

If you'd like to know more about the DigiVox – or our *rental program* – call us toll-free, at 1-800-344-1778.

TECHNOLOGY INC.

Circle # 161

State Assistive Technology Programs

The following state assistive technology programs are funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under the Technology-Related Assistance For Individuals With Disabilities Act of 1988 (and Amendments of 1994). For more information, contact the RESNA Technical Assistance Project, 1700 North Moore St., Ste. 1540, Arlington, VA 22209-1903; (703) 524-6686, (voice); (703) 524-6630, (TTY).

A description of services provided by individual programs follows each listing. Numbers correspond to items listed in the Key to Services.

This symbol (✦) indicates an Internet e-mail address.

ALABAMA

Statewide Technology Access and Response System for Alabamians with Disabilities
2125 E South Blvd
PO Box 20752
Montgomery, AL 36120-0752
(205) 288-0240 (voice)
(205) 281-2276 (TTY)
(205) 288-7171 (fax)
1,2,4,5

ALASKA

Assistive Technologies of Alaska
701 E Tudor Rd, Ste 280
Anchorage, AK 99503-7445
(907) 563-0318 (V/TTY)
(907) 563-0146 (fax)
1,2,3,4,5,6,8

AMERICAN SAMOA

Assistive Technology Project
Division of Vocational Rehabilitation
Department of Human Resources
Pago Pago, American Samoa 96799
(684) 633-5010 (voice)
(684) 633-7874 (TTY)
(684) 633-2393 (fax)
1,2,3,4,5,7,8,9

ARIZONA

Arizona Technology Access Program
2600 N Wyatt Dr, 2nd Fl
Tucson, AZ 85712
(800) 477-9921 (voice; AZ only)
(602) 324-3170 (voice)
(602) 324-3177 (TTY)
(602) 324-3176 (fax)
✦ demetras@ccit.arizona.edu
1,2,3,4,5,6,8 (some services still under development)

ARKANSAS

Increasing Capabilities Access Network
2201 Brookwood, Ste 117
Little Rock, AR 72202
(800) 828-2799 (V/TTY; AR only)
(501) 666-8868 (V/TTY)
(501) 666-5319 (fax)
1,2,3,4,5,6,9

CALIFORNIA

California Assistive Technology System
CA Department of Rehabilitation
830 K St
Sacramento, CA 95814
(916) 324-3062 (V/TTY)
(916) 324-7386 (TTY)
(916) 323-0914 (fax)
1,7; newsletter

COLORADO

The Colorado Assistive Technology Program
Rocky Mountain Resource and Training Institute
6355 Ward Rd, Ste 310
Arvada, CO 80004
(800) 255-3477 (V/TTY; CO only)
(303) 420-2942 (V/TTY)
(303) 420-8675 (fax)
1,2,3,4; technology-related advocacy

CONNECTICUT

Assistive Technology Project
Bureau of Rehabilitation Services
10 Griffin Rd N
Windsor, CT 06095
(203) 298-2042 (voice)
(203) 298-2018 (TTY)
(203) 298-9590 (fax)
1,2,5,7

DELAWARE

Delaware Assistive Technology Initiative
University of Delaware
Al duPont Institute
1600 Rockland Rd, Rm 154
Wilmington, DE 19899
(302) 651-6790 (voice)
(302) 651-6794 (TTY)
(302) 651-6793 (fax)
1,2,3,4,5,6,8

DISTRICT OF COLUMBIA

Partnership for Assistive Technology
National Rehabilitation Hospital
801 Pennsylvania Ave SE, Ste 210
Washington, DC 20003
(202) 639-9510 (voice)
(202) 639-0477 (TTY)
(202) 639-0478 (fax)
1,2,3,4,5,6,7,8

FLORIDA

Alliance for Assistive Service and Technology
2002 Old St Augustine Rd, Bldg A
Tallahassee, FL 32399-0696
(904) 487-3278 (V/TTY)
(904) 488-8062 (fax)
1,3

GEORGIA

Tools for Life
Division of Rehabilitation Services
2 Peachtree St NW, Ste 23-411
Atlanta, GA 30303
(800) 497-8665 (voice; GA only)
(404) 657-3084 (V/TTY)
(404) 657-3085 (TTY)
(404) 657-3086 (fax)
1,2,3,4,6,8,9; annual conference, seven regional technology demonstration centers

GUAM

System for Assistive Technology
University Affiliated Program—Developmental Disabilities
University of Guam
UOG Station
Mangilao, Guam 96923
(671) 734-9309 (voice)
(671) 734-5709 (fax)
✦ sspencer@uog.edu
1,2,3,5

Key to Services

1. **Information and referral services**
2. **Assistance in obtaining funding for assistive devices and services**
3. **Equipment demonstration center**
4. **Equipment loan program**
5. **Training in assistive technology use**
6. **Equipment exchange and recycling program**
7. **Financial loan program for the purchase of assistive technology and services**
8. **Peer support groups**
9. **Mobile van outreach service**

HAWAII

Assistive Technology Training and Services
677 Ala Moana Blvd, Ste 403
Honolulu, HI 96813
(808) 532-7110 (V/TTY)
(808) 532-7120 (fax)
1,2,4,5,7,9; video loans

IDAHO

Assistive Technology Project
129 W Third St
Moscow, ID 83843
(800) 432-8324 (V/TTY; ID only)
(208) 885-3559 (voice)
(208) 885-3628 (fax)
✦ fifield@uidaho.edu
1,2,3,5,6,7,8; regional resource centers

ILLINOIS

Assistive Technology Project
110 Iles Park Pl
Springfield, IL 62718
(800) 852-5110 (V/TTY; IL only)
(217) 522-7985 (V/TTY)
(217) 522-8067 (fax)
✦ ilat@gteens.com
1,2,3,4,5,9

STATE ASSISTIVE TECHNOLOGY PROGRAMS

ATTAIN: Accessing Technology Through Awareness in Indiana Project
PO Box 7083
402 W Washington St, Rm W453
Indianapolis, IN 46207-7083
(800) 545-7763 (V/TTY)
(317) 232-1410 (V/TTY)
(317) 232-6478 (fax)
1,2,5,6,8,9

Iowa Program for Assistive Technology
Iowa University Affiliated Program
University Hospital School
Iowa City, IA 52242
(800) 331-3027 (V/TTY)
(319) 353-6386 (V/TTY)
(319) 356-8284 (fax)
1,2,5,6,8

Assistive Technology for Kansans Project
2601 Gabriel
Parsons, KS 67357
(316) 421-8367 (voice)
(316) 421-0954 (TTY)
(316) 421-0954 (fax)
1,2,3,4,5,6,8

Assistive Technology Services Network
427 Versailles Rd
Frankfort, KY 40601
(800) 327-5287 (voice)
(502) 573-4665 (V/TTY)
(502) 573-3976 (fax)
1,2,3,4,5,6; four regional centers

Louisiana Assistive Technology Access Network
PO Box 3455, Bin #14
Baton Rouge, LA 70821-3455
(800) 922-3425 (voice)
(800) 256-1633 (TTY)
(504) 342-8821 (voice)
(504) 342-1970 (fax)
1,2,3,5; rural/low-income/minority outreach

Consumer Information and Technology Training Exchange
Maine CITE Coordinating Ctr
Education Network of Maine
46 University Dr
Augusta, ME 04330
(207) 621-3195 (V/TTY)
(207) 621-3193 (fax)
5; Coordinates sub-grant activities which provide direct services

Technology Assistance Program
Governor's Office for Individuals with Disabilities
300 W Lexington St, Box 10
Baltimore, MD 21201
(800) 832-4827 (V/TTY)
(410) 333-4975 (V/TTY)
(410) 333-6674 (fax)
1,2,3,4,5,6,7; theatre audio description, rural/minority outreach

Massachusetts Assistive Technology Partnership Center
Children's Hospital
1295 Boylston St, Ste 310
Boston, MA 02215
(800) 848-8867 (V/TTY; MA only)
(617) 735-7820 (voice)
(617) 735-7301 (TTY)
(617) 735-6345 (fax)
(800) 950-6287 (2400-baud BBS; MA only)
(617) 267-5027 (2400-baud BBS)
1,2,5; newsletter, fact sheets, curricular and training materials, needs assessments

Tech 2000
PO Box 30010
Lansing, MI 48909-7510
(517) 335-6874 (voice)
(517) 373-4035 (TTY)
(517) 373-0565 (fax)
1,8

Star Program
300 Centennial Bldg
658 Cedar St
St Paul, MN 55155
(800) 657-3862 (voice)
(800) 657-3896 (TTY)
(612) 282-6671 (fax)
1,2,5,6,8,9; regional resource centers, graduate-student internships

Project Start
PO Box 1000
Jackson, MS 39205-1000
(800) 852-8328 (V/TTY; MS only)
(601) 987-4872 (V/TTY)
(601) 364-2349 (fax)
1,2,3,4,5

Assistive Technology Project
4731 S Cochise, Ste 114
Independence, MO 64055-6975
(816) 373-5193 (voice)
(816) 373-9315 (TTY)
(816) 373-9314 (fax)
1,2,3,5,6,8; individual advocacy training

Montech
University of Montana, MUARID, MonTECH
634 Eddy Ave
Missoula, MT 59812
(800) 732-0323 (V/TTY)
(406) 243-4730 (fax)
1,2,3,4,6,7,8; six regional outreach centers

Assistive Technology Project
301 Centennial Mall S
PO Box 94987
Lincoln, NE 68509-4987
(402) 471-3647 (V/TTY)
(402) 471-0117 (fax)
mschultz@nde4.nde.state.ne.us
1,2,3,4,5,6,8

Assistive Technology Project
Rehabilitation Division
Office of Community Based Services
711 S Stewart St
Carson City, NV 89710
(702) 687-4452 (voice)
(702) 687-3388 (TTY)
(702) 687-3292 (fax)
Referrals to local resources

Assistive Technology Partnership Project
University of New Hampshire
Institute on Disability/UAP
Ten Ferry St, Unit #14
Concord, NH 03301-5019
(800) 427-3338 (V/TTY; NH only)
(603) 224-0630 (V/TTY)
(603) 226-0389 (fax)
1,2,3,4,5,6,7

Technology Assistive Resource Program
135 E State St, CN 398
Trenton, NJ 08625
(800) 342-5832 (voice; NJ only)
(800) 382-7765 (TTY; NJ only)
(609) 292-8347 (voice)
(609) 292-4616 (fax)
1,2,3,6,8

Key to Services

1. **Information and referral services**
2. **Assistance in obtaining funding for assistive devices and services**
3. **Equipment demonstration center**
4. **Equipment loan program**
5. **Training in assistive technology use**
6. **Equipment exchange and recycling program**
7. **Financial loan program for the purchase of assistive technology and services**
8. **Peer support groups**
9. **Mobile van outreach service**

Technology Assistance Program
435 St Michael's Dr, Bldg D
Santa Fe, NM 87503
(800) 866-2253 (V/TTY)
(505) 827-3746 (fax)
stdvnmtap@technet.nm.org
1,2,3,4,5,6,7,8,9

State TRAID Project
Office of Advocates for Persons with Disabilities
One Empire State Plaza, Ste 1001
Albany, NY 12223-1150
(800) 522-4369 (V/TTY; NY only)
(518) 474-2825 (voice)
(518) 473-4231 (TTY)
(518) 473-6005 (fax)
1,2,3,4,5,6

Assistive Technology Project
Dept of Human Resources
Division of Vocational Rehabilitation Services
1110 Navaho Dr, Ste 101
Raleigh, NC 27609
(800) 852-0042 (voice)
(919) 850-2787 (V/TTY)
(919) 850-2792 (fax)
atp@med.unc.edu
1,2,3,5,6,8

STATE ASSISTIVE TECHNOLOGY PROGRAMS

Interagency Program for Assistive Technology
PO Box 743
Cavalier, ND 58220
(701) 265-4807 (V/TTY)
(701) 265-3150 (fax)
leej@warp6.cs.misu.nodak.edu
1,2,4,5,9

Assistive Technology Project
Governor's Developmental Disabilities Council
PO Box 2565
Saipan, MP 96950
(670) 322-3014 (V/TTY)
(670) 322-4168 (fax)
1,2,6

TRAIN: Technology-Related Assistance Information Network
Ohio SuperComputer Ctr
1224 Kinnear Rd
Columbus, OH 43212
(800) 784-3425 (V/TTY; OH only)
(614) 292-2426 (V/TTY)
(614) 292-5866 (fax)
1,2,3,5,6,7,8; electronic network on assistive technology with school districts

Oklahoma! ABLE Tech
Dept of Rehabilitation Services
PO Box 36659
Oklahoma City, OK 73136
(800) 316-4119 (V/TTY; OK only)
(405) 427-3312 (V/TTY)
(405) 427-3027 (fax)
willing@ix.netcom.com
1,2,3,4,5,8

Technology Access for Life Needs Project
Chemeketa Community College
PO Box 14007
Salem, OR 97309-7070
(800) 677-7512 (V/TTY; OR only)
(503) 399-4950 (V/TTY)
(503) 399-6978 (fax)
susan.mcnaught@p10.f99.n105.z1.fidonet.org
1,2,3,4,5,6

Pennsylvania's Initiative on Assistive Technology
Institute on Disabilities/UAP
Temple University
Ritter Hall Annex 433 (004-00)
Philadelphia, PA 19122
(800) 204-7428 (V/TTY)
(215) 204-1356 (V/TTY)
(215) 204-6336 (fax)
piat@astro.ocis.temple.edu
1,2,3,4,5,6,8

Assistive Technology Project
University of Puerto Rico
Medical Sciences Campus
College of Health-Related Professions
Dept of Communicological Disorders
Box 365067
San Juan, PR 00936-5067
(800) 496-6035 (From US mainland)
(800) 981-6033 (PR only)
(809) 764-6035 (voice)
(809) 754-8034 (TTY)
(809) 759-3645 (fax)
1,2,3,5

Assistive Technology Access Project
Dept of Human Services, Div of Community Services
Office of Rehabilitation Services, Voc Rehab
40 Fountain St, 5th Fl
Providence, RI 02903-1898
(800) 752-8088, ext 2608 (RI only)
(401) 421-7005 (voice)
(401) 421-7016 (TTY)
(401) 421-9259 (fax)
1,2,4

Assistive Technology Program
Vocational Rehabilitation Dept
PO Box 15, 1410-C Boston Ave
West Columbia, SC 29171-0015
(803) 822-5404 (V/TTY)
(803) 822-4301 (fax)
1,2,3,4,5,6,7,8,9

Dakota Link
1925 Plaza Blvd
Rapid City, SD 57702
(800) 645-0673 (V/TTY; SD only)
(605) 344-1876 (V/TTY)
(605) 394-5315 (fax)
1,2,3,4,5,6,9; six rural outreach centers

Technology Access Project
710 James Robertson Pkwy
Gateway Plaza, 11th Fl
Nashville, TN 37243-0675
(800) 732-5059 (voice; TN only)
(615) 532-6530 (voice)
(615) 532-6612 (TTY)
(615) 532-6964 (fax)
1,2,3,4,5,9

Assistive Technology Partnership
University of Texas at Austin, UAP of Texas
Department of Special Education, EDB 306
Austin, TX 78712
(800) 828-7839 (voice)
(512) 471-7621 (voice)
(512) 471-1844 (TTY)
(512) 471-7549 (fax)
1,3,5,8,9

Utah Center for Assistive Technology
2056 South 1100 East
Salt Lake City, UT 84106
(800) 333-8824 (V/TTY)
(801) 485-9152 (V/TTY)
(801) 797-2355 (fax)
1,2,3,4,5,6,7

Assistive Technology Project
103 S Main St, Weeks I
Waterbury, VT 05671-2305
(802) 241-2620 (V/TTY)
(802) 241-3052 (fax)
1,2,3,4,5,6,7

Assistive Technology System
8004 Franklin Farms Dr
PO Box K–300
Richmond, VA 23288-0300
(800) 435-8490 (V/TTY; VA only)
(804) 662-9998 (V/TTY)
(804) 662-9478 (fax)
Database BBS: (800) 238-7955 (VA only; 2400 baud)
Equipment exchange BBS (804) 662-9477 (2400 baud)
1,3,6 (through BBS only)

Assistive Technology Alliance
DSHS/DVR
PO Box 45340
Olympia, WA 98504-5340
(206) 438-8051 (V/TTY)
(206) 438-8644 (TTY)
(206) 438-8007 (fax)
dhooks@wlu.com
1,2,3,6,9; legal advocacy, universal access to library systems

West Virginia Assistive Technology System
Airport Office and Research Park
955 Hartman Run Rd
Morgantown, WV 26505
(800) 841-8436 (voice; WV only)
(304) 293-4692 (V/TTY)
(304) 293-7294 (fax)
reb@wvnvm.wvnet.edu
1,2,3,4,5,8; newsletter, advocacy training

WisTech
Division of Vocational Rehabilitation
PO Box 7852
1 W Wilson St, Rm 950
Madison, WI 53707-7852
(608) 266-1281 (voice)
(608) 266-9599 (TTY)
(608) 267-3657 (fax)
trampf@aol.com
1,2,3,4,5,6,8; advocacy, legal assistance

WYNOT: Wyoming's New Options In Technology
Division of Vocational Rehabilitation
1100 Herschler Bldg
Cheyenne, WY 82002
(800) 877-9975 (voice)
(800) 877-9965 (TTY)
(307) 777-7450 (voice)
(307) 777-5939 (fax)
1,2,3,4,5; community resource team development and training

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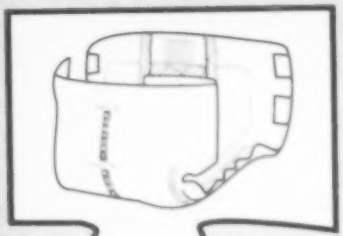

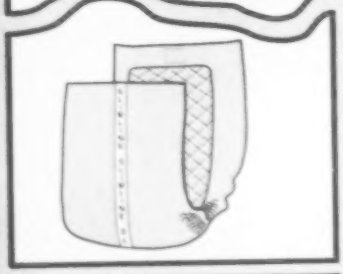

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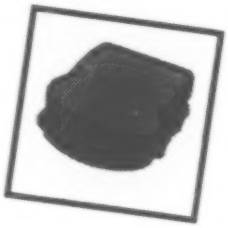

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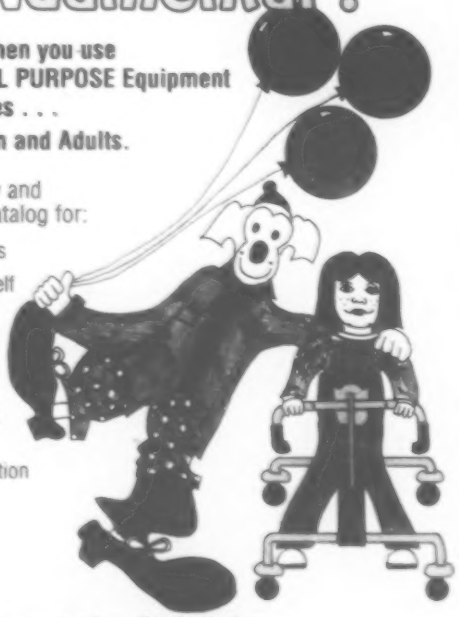

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DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS

The disability-related bulletin board services (BBSs) listed below can provide a wealth of helpful information. Use of all listed services is free, however, depending on where one lives, calling a BBS may incur long-distance telephone charges. A few bulletin boards charge fees for increased access or membership; when applicable, these fees are mentioned in the notes following each entry. Some boards chose to list voice numbers where the coordinator of the BBS, known as the system operator (sysop), can be reached for questions or comments.

Unlike major commerical online services, these services do not provide special software. Instead, users must call the BBS using the communications software that came with their modems. Users must be sure to stay within the given baud rate per second for modems (bps)—this figure is listed after the BBS modem number (i.e., "up to 9,600 bps"). This is the only aspect of the communications software that the user must configure (set) differently for various BBSs; the other modem settings are the same for all listed services—8 data bits, no parity, 1 stop bit (8-N-1). (These are the default settings for most communications software—you don't need to understand what each means; you may not even need to change the configuration of your software from the default.)

Once connected to a BBS, users can post and read messages, upload (post) and download (receive) files and leave messages for the sysop. Certain boards are connected to larger networks, such as Internet, Fidonet or ADAnet, which allow files to be shared and messages to be posted among a large number of bulletin boards.

ALABAMA

ADAnet
(205) 254-6050, up to 2,400 bps
All disability groups covered; many BBSs are linked to this system; many message areas, large file area for downloading; users get 30 free minutes daily; subscriptions ($40/yr) allow increased usage and unlimited downloading.

ALASKA

Assistive Technology of Alaska BBS
(800) 770-1399 (AK only), up to 2,400 bps
(907) 277-1399 (out-of-state), up to 2,400 bps
(800) 636-0138 (voice)
(907) 563-0140 (voice)
Forums on specific disabilities, education, assistive technology, legislation; files for downloading.

ARIZONA

Tucson Prologue
(602) 322-8014, up to 14,400 bps
General disabilities, some emphasis on blindness; Internet e-mail, Fidonet; message areas, files for downloading; local issues; most users are adults with disabilities.

CALIFORNIA

BayTalk
(415) 864-6430; up to 9,600 bps
Emphasis on computer-access issues for persons with disabilities; message/file areas concerning Americans with Disabilities Act, info for parents on local issues.

Blink Connection
(510) 276-4121, up to 2,400 bps
Emphasis on visual impairments; message areas; some Fidonet access; BBS can be used by persons with visual impairments.

Disabled Children's Computer Group
(510) 841-5621, up to 9,600 bps
(510) 841-3224 (voice)
Emphasis on children with disabilities; conferences for adults, families—parents are welcome; Fidonet; info on local resources, files for downloading.

KIRO Education BBS
(805) 324-2955, up to 14,400 bps
Emphasis on blindness, education; BBS use is free/$5.00 monthly fee for Internet access; Fidonet, Internet e-mail/newsgroups; National Federation of the Blind forums, publications online—helpful materials for parents.

LINCS–BBS
(408) 294-6933, up to 14,400 bps
(408) 277-0764, up to 14,400 bps
(408) 288-5010 (voice)
General disabilities, emphasis on children; Parents Helping Parents (PHP) members ($25 annual fee) receive Internet e-mail; message areas, "Parents Search" area, resource directories, info on rare conditions, local legislative updates; files/games for downloading; PHP can provide technical assistance to resource centers interested in starting their own BBSs.

CONNECTICUT

Handicap News BBS
(203) 926-6168, up to 14,400 bps
(203) 926-6187 (voice)
Wide range of disabilities—50-80 conference areas; Internet e-mail/newsgroups, Fidonet; many conferences helpful to parents, local conference available, although most callers are non-local; nearly 1000 files for downloading; sysop is parent of child who has Down syndrome.

DISTRICT OF COLUMBIA

ACB On-Line (American Council of the Blind)
(202) 331-1058, up to 14,400 bps
(202) 467-5081 (voice)
Emphasis on visual impairments; files on braille literacy, resource lists, archive of ACB literature.

ILLINOIS

COPH 2 BBS
(312) 436-0559, up to 2,400 bps
General disabilities; message areas, files for downloading.

INDIANA

The Special Needs BBS
(219) 659-0112, up to 14,400 bps
General disabilities, some emphasis on hearing impairments; Internet e-mail, Fidonet, Health Care Net access; message areas for parents, files/programs for downloading; sysop is parent of child who is deaf.

MAINE

Maine Meeting Place BBS
(800) 339-3845 (ME only), up to 28,800 bps
(207) 324-5310 (Outside ME), up to 28,800 bps
(207) 324-2337 (voice)
Wide range of disabilities, related issues; BBS designed to accommodate computer novices—many parents are users; Internet e-mail/newsgroups; local issues; outreach to groups/individuals who need low-cost computer equipment.

MARYLAND

ABLE INFORM
(301) 589-3563, up to 9600 bps
Emphasis on assistive technology and rehabilitation/disability literature; Searchable databases, resource guides, fact sheets.

Braille Inn BBS
(410) 893-8944, up to 9,600 bps
General disability issues; files in and about braille; Fidonet.

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DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS

Deaf New World BBS
(301) 587-2277,
up to 14,400 bps
(301) 588-0965 (TTY)
(301) 588-0548 (voice)
(301) 588-5261 (fax)
Emphasis on deafness; TTY-compatible; 30 minutes free access daily—subscribers (varying rates) receive more time and Internet e-mail; Fidonet; online shopping areas for deaf-related products; files for downloading.

HEX BBS
(301) 593-7357, up to 9,600 bps
General disabilities; TTY-compatible; Fidonet; message areas, files for downloading.

NFB Net (National Federation of the Blind)
(410) 752-5011,
up to 14,400 bps
(410) 659-9314 (voice)
Emphasis on visual impairments; NFB literature/publications online, conferences for parents to discuss issues with adults who are blind; Fidonet, ADAnet; electronic books/text files for downloading.

MASSACHUSETTS

Disabled Individuals Movement for Equality Network (DIMENET)
(508) 880-5412,
up to 14,400 bps
(513) 237-8360 (voice)
DIMENET is a coalition of Independent Living Center (ILC) BBSs working to obtain resources for online computing for all ILCs. The BBSs are based in Taunton, MA; Dayton, OH and Tulsa, OK; general disabilities, ILC related issues; Internet e-mail/newsgroups; Fidonet; files for downloading.

Mass. Commission for the Blind BBS
(617) 451-5327,
up to 14,400 bps
(800) 392-6450 (voice; MA only)
(617) 727-5550 (voice)
Emphasis on visual impairments; message areas, conferences, employment info, conference info for parents; files for downloading.

VIBUG BBS (Visually Impaired/Blind Users Group)
(617) 767-2909,
up to 14,400 bps
Emphasis on visual impairments; conferences for parents; Fidonet; files for downloading.

MICHIGAN

Blind Ambition BBS
(810) 651-4009,
up to 2,400 bps
Sponsored by Leader Dogs for the Blind, Rochester Hills, MI; emphasis on visual impairments; message areas, files/programs for blind users for downloading.

MINNESOTA

Blind Services BBS
(612) 642-0483, up to 2,400 bps
Sponsored by Minnesota Services for the Blind; some emphasis on visual impairments; Fidonet; message areas, files for downloading.

Disability Resources Affiliates & Groups Network (DRAGNET)
(612) 753-1943,
up to 14,400 bps
(612) 827-2294 (V/TTY)
Wide range of disability issues; free access, user guide available for suggested $5 donation; Internet, Fidonet, ADAnet; conferences for parents, will put other groups' newsletters online for free; many non-local callers; files for downloading.

MISSOURI

SSMART BBS
(314) 781-6397, up to 9,600 bps
(314) 768-5312 (voice)
Forums on brain injuries, stroke, spinal cord injuries, other disabilities; forum for parents; local issues; files for downloading.

NEW JERSEY

Disabilities Electronic Network (DEN)
(201) 342-3273,
up to 14,400 bps
(201) 342-6984 (voice)
Wide range of disabilities; Fidonet, ADAnet; message areas on specific disabilities, message area for parents, files for downloading.

NEW YORK

Access BBS
(518) 885-4192,
up to 16,800 bps
General disabilities; Internet e-mail, Fidonet, ADAnet, AEGIS (AIDS Education General Information Service); files specific to children with disabilities, resource info, local conferences, files for downloading.

Maxwell Monde, 18 months, enjoys sitting in the jacuzzi with his dad, David. Max developed a grade IV intraventricular hemorrhage and hydrocephalus before birth. As a result, he has mild cerebral palsy and a visual impairment. Max, who loves any activity involving water, enjoys bathtime almost as much as those father-son soaks in the jacuzzi.

OHIO

Disabled Individuals Movement for Equality Network (DIMENET)
(513) 439-0557,
up to 14,400 bps
(513) 237-8360 (voice)
See DIMENET/Massachusetts.

OKLAHOMA

Disabled Individuals Movement for Equality Network (DIMENET)
(918) 582-3622,
up to 14,400 bps
(513) 237-8360 (voice)
See DIMENET/Massachusetts.

OREGON

The DisAbility BBS
(503) 777-6561,
up to 14,400 bps
General disabilities; 42 conference/message areas—LD, ADD areas recommended for parents; Fidonet, ADAnet; files for downloading.

PENNSYLVANIA

Sounding Board BBS
(412) 621-4604,
up to 14,400 bps
Emphasis on deaf-blind, visual/hearing impairments; conferences for specific disabilities; Fidonet; files for downloading.

TEXAS

CCAD Online
(214) 647-5739, up to 2,400 bps
Emphasis on assistive technology, education; BBS mostly accessible for persons using assistive technology; message areas, files for downloading.

Microtalk BBS
(903) 832-3722, up to 2,400 bps
General disabilities, local issues, message areas, files for downloading.

VIRGINIA

Handiline BBS
(703) 536-4182, up to 9,600 bps
General disabilities, local issues; message areas.

WEST VIRGINIA

Project Enable
(304) 759-0727, up to 9,600 bps
General disabilities; Fidonet, ADAnet; many message areas.

CANADA

ONTARIO

Abilities OnLine
(416) 650-5411,
up to 14,400 bps
(416) 650-6207 (voice)
Wide range of disabilities; message areas mainly for kids, some for parents; ADAnet, Internet e-mail/newsgroups; resources for parents; files for downloading.

Disability Access
(613) 837-5473, up to 9,600 bps
General disabilities; local issues; resource information.

BRITISH COLUMBIA

TASH On-Line Disability Resources
(604) 856-3661,
up to 14,400 bps
(604) 856-4778 (voice)
Wide range of disabilities, health/education issues; Fidonet, Health care net, Internet; local resources; software for preschoolers/files for downloading; will provide assistance to anyone who wants to start a BBS.

Life Planning Should Be A Team Effort

Providing for the future needs of a family member with a disability can be a complicated matter. Families often need the help of those with specific knowledge and experience to be certain they are making the best choices for their loved one. The Life Planning Team shown here includes the person with a disability, family members, attorney and EPPD Representative.

Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidelines to hundreds of families every month. Our national network of skilled and experienced local attorneys and estate planners can assist families with a son or daughter who has a disability to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD representatives provide FREE initial interviews to determine your needs and FREE group seminars for parents. We have an office near you. EPPD is not a guardianship or master trust plan, but assists parents in locating the services necessary to provide a secure future for their loved one.

Read the following comments from just a few of our satisfied clients:

"I appreciate the good service I received in planning for my disabled daughter's future. I liked the way you handled everything, going through the many details with me thoroughly."
Marie G. Savard, Glendale, CA

"Our EPPD Planner did a great job in helping us to finalize all the essential areas of planning for our daughter's future. She stepped in and helped fill in the gaps that we had not considered. We are confident and feel good that her future will be secure."
Jim and Michele Lee, Fort Collins, CO

"We are enormously pleased with all the work our EPPD planner did for us. We are very pleased with the results, as we know our daughter's future is secure."
Lois and Carl Westlund, Ocean Shores, WA

"Your presentation was most informative on planning for the financial security of our disabled loved one. We greatly appreciate the knowledge you shared with us." *Sandra J. Barcus, Scottsdale Head Injury Support Group, Scottsdale, AZ*

"The EPPD seminar was great. More people should take advantage of this opportunity and learn how to prepare for the future." *Pam Weiner, Haverhill, MA*

"Our EPPD planner has been an invaluable resource to our community. His knowledge, experience and commitment has been a blessing for many families."
Evelyn G. Johnson, Houston, TX

"Your presentation on estate planning was well received and we received a lot of positive feedback. Information on this topic can sometimes be overwhelming, but you present the material in a clear, concise manner."
Deborah Wilson, Missouri Head Injury Association, Jefferson City, MO

"The work our estate planner did helped to put our minds at ease. It was very thorough."
Karen Cockehan, New Orleans, LA

"Just the kind of planning I had been looking for. The seminar helped me to understand just what we needed to do in order to provide for our son."
Connie Griffin, Athens, AL

"We found the process EPPD used worked well for us. They brought together all the planning services necessary to allow us to reduce our concerns." *Mr. and Mrs. S. Butler, Albuquerque, NM*

Call today to receive a FREE brochure and the location of your local EPPD representative.
EPPD would be pleased to do an educational seminar for your group.

800-448-1071
Richard W. Fee,
Executive Director
National Office
1200 Corporate Drive
Suite 330
Birmingham, Alabama 35242
TTY 800-934-1929
FAX 800-880-9327

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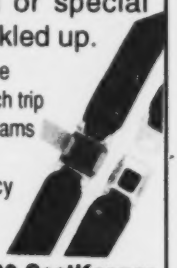

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1-800-241-1848

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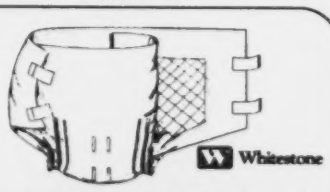

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Its unique ball-joint movements and sturdy supports put MYDESC in a class of its own. It tilts for reading, writing or computing, then goes flat for lunch time and breaks. A secret storage compartment hides papers, books, pencils (and maybe a few comic books). And when it's time for transfers, the entire desktop swings down to the side and out of the way.

It's simply designed for flexibility and growth, so he can use his MYDESC for years to come!

For more information on the entire MYDESC line, contact your local rehab dealer and ask to see the MYDESC demonstration video. Or call us directly for a free brochure.

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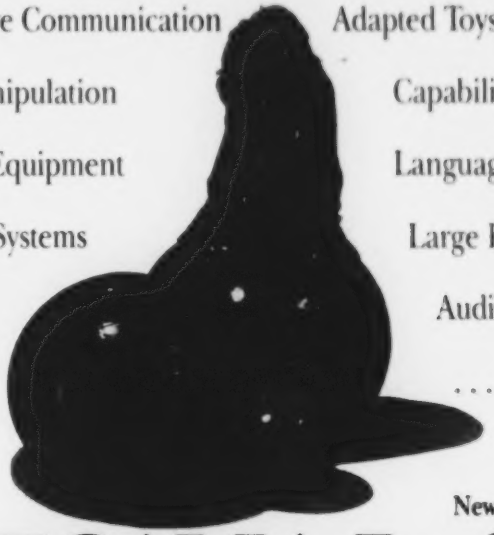

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- Head Injury
- Birth Defects
- Cerebral Palsy
- Feeding Disorders
- Behavior Problems
- Down Syndrome
- Other Special Needs

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Baltimore, MD 21205

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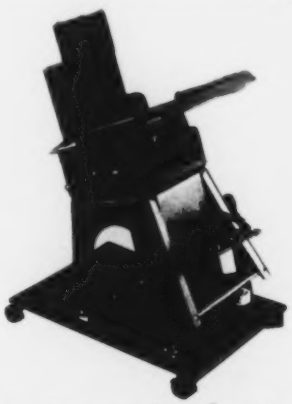

the youngster to sit independently securely and in correct position. Available with a wheeled base and tilt in space feature.

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105

FEDERAL & FEDERALLY-FUNDED INFORMATION RESOURCES

The federal government supports many clearinghouses, information centers and institutes that focus on specific topics. In addition to publishing and distributing extensive free material on disability-related subjects, many of the clearinghouses, centers and institutes also provide referrals to local resources.

For more information on federal and federally-funded information resources, contact:

- ***NICHCY** (National Information Center for Children and Youth with Disabilities), 1875 Connecticut Ave NW, Washington, DC 20009, (800) 695-0285 (V/TTY), (202) 884-8741 (fax).*
- ***NARIC** (National Rehabilitation Information Center), 8455 Colesville Rd, Ste 935, Silver Spring, MD 20910, (800) 346-2742, (301) 588-9284 (V/TTY), (301) 587-1967 (fax).*
- ***NHIC** (National Health Information Center), P.O. Box 1133, Washington, DC 20013-1133, (800) 336-4797 (voice), (301) 984-4256 (fax).*

GENERAL

Clearinghouse on Disability Information
Office of Special Education and Rehabilitation Services
US Dept of Education
330 C St SW
Switzer Bldg, Rm 3132
Washington, DC 20202-2524
(202) 205-8241 (V/TTY)
(202) 205-9252 (fax)

National Center for Education in Maternal and Child Health
2000 15th St N, Ste 701
Arlington, VA 22201-2617
(703) 524-7802 (voice)
(703) 524-9335 (fax)

National Health Information Center
PO Box 1133
Washington, DC 20013-1133
(800) 336-4797 (voice)
(301) 984-4256 (fax)

National Information Center for Children and Youth with Disabilities (NICHCY)
1875 Connecticut Ave NW
Washington, DC 20009
(800) 695-0285 (V/TTY)
(202) 884-8741 (fax)

National Institute of Child Health and Human Development
PO Box 29111
Washington, DC 20040
(301) 496-5133 (voice)
(301) 496-7101 (fax)

National Maternal and Child Health Clearinghouse
8201 Greensboro Dr, Ste 600
McLean, VA 22102
(703) 821-8955, ext 254, 265 or 317 (voice)
(703) 821-2098 (fax)

National Rehabilitation Information Center (NARIC)
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910
(800) 346-2742 (V/TTY)
(301) 588-9284 (V/TTY)
(301) 587-1967 (fax)

Office of Minority Health Resource Center
PO Box 37337
Washington, DC 20013
(800) 444-6472 (voice)
(301) 565-5112 (fax)

AIDS

Centers for Disease Control and Prevention National AIDS Clearinghouse
PO Box 6003
Rockville, MD 20849-6003
(800) 458-5231 (voice)
(800) 342-AIDS (English hotline)
(800) 344-SIDA (Spanish hotline)
(800) 243-7012 (TTY)
(301) 738-6616 (fax)
(301) 217-0023 (international line)

National Pediatric HIV Resource Center
15 S 9th St
Newark, NJ 07107
(800) 362-0071 (voice)
(201) 268-8251 (voice)
(201) 485-2752 (fax)

ALLERGY & INFECTIOUS DISEASES

National Institute of Allergy and Infectious Diseases
Office of Communication
Bldg 31, Rm 7A50
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-5717 (voice)
(301) 402-0120 (fax)

ASSISTIVE TECHNOLOGY & REHABILITATION

ABLEDATA
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910-3319
(800) 227-0216 (V/TTY)
(301) 588-9284 (V/TTY)
(301) 587-1967 (fax)

CANCER

Cancer Information Service
National Cancer Institute
Bldg 31, Rm 10A16
Bethesda, MD 20892
(800) 422-6231 (voice)

DEAF-BLIND

National Information Clearinghouse on Children Who Are Deaf-Blind
345 N Monmouth Ave
Monmouth, OR 97361
(800) 438-9376 (voice)
(800) 854-7013 (TTY)
(503) 838-8150 (fax)

DIABETES

National Diabetes Information Clearinghouse
1 Information Wy
Bethesda, MD 20892-3560
(301) 654-3327 (voice)
(301) 907-8906 (fax)

DIGESTIVE DISEASES

National Digestive Diseases Information Clearinghouse
2 Information Wy
Bethesda, MD 20892-3570
(301) 654-3810 (voice)
(301) 907-8906 (fax)

EDUCATION

ERIC Clearinghouse on Disabilities and Gifted Education
Council for Exceptional Children
1920 Association Dr
Reston, VA 22091-1589
(800) 328-0272 (voice)
(703) 264-9474 (voice)
(703) 620-3660 (TTY)

National Clearinghouse on Postsecondary Education for Individuals with Disabilities
HEATH Resource Center
1 Dupont Cir NW, Ste 800
Washington, DC 20036-1193
(800) 544-3284 (V/TTY)
(202) 939-9320 (V/TTY)
(202) 833-47560 (fax)

HEARING IMPAIRMENTS

National Information Center on Deafness
Gallaudet University
800 Florida Ave NE
Washington, DC 20002-3695
(202) 651-5051 (voice)
(202) 651-5052 (TTY)
(202) 651-5054 (fax)

National Institute on Deafness and Other Communication Disorders Information Clearinghouse
1 Communication Ave
Bethesda, MD 20892-3456
(800) 241-1044 (voice)
(800) 241-1055 (TTY)

HEART, LUNG & BLOOD DISORDERS

National Heart, Lung, and Blood Institute Information Center
PO Box 30105
Bethesda, MD 20824-0105
(301) 251-1222 (voice)
(301) 251-1223 (fax)

HOUSING

Housing and Urban Development User
PO Box 6091
Rockville, MD 20850
(800) 245-2691 (voice)
(800) 887-8339 (TTY)
(301) 251-5747 (fax)

KIDNEY & UROLOGIC DISEASES

National Kidney and Urologic Diseases Information Clearinghouse
3 Information Wy
Bethesda, MD 20892-3580
(301) 654-4415 (voice)
(301) 907-8906 (fax)

MENTAL HEALTH

National Clearinghouse on Family Support and Children's Mental Health
Portland State University
PO Box 751
Portland, OR 97207-0751
(800) 628-1696 (voice)
(503) 725-4040 (voice)
(503) 725-4165 (TTY)
(503) 725-4180 (fax)

National Institute of Mental Health
Information Resources and Inquiries Branch
5600 Fishers Ln, Rm 7C-02
Rockville, MD 20857
(301) 443-4513 (voice)
(301) 443-8431 (TTY)

MUSCULOSKELETAL & SKIN DISEASES

National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse
1 AMS Cir
Bethesda, MD 20892-3675
(301) 495-4484 (voice)
(301) 587-4352 (fax)

NEUROLOGICAL DISORDERS

National Institute of Neurological Disorders & Stroke
PO Box 5801
Bethesda, MD 20824
(800) 352-9424 (voice)
(301) 496-5751 (voice)
(301) 402-2186 (fax)

ORAL HEALTH

National Oral Health Information Clearinghouse
1 NOHIC Wy
Bethesda, MD 20892
(301) 402-7364 (voice)
(301) 907-8830 (fax)

PRIMARY CARE

National Clearinghouse for Primary Care Information
8201 Greensboro Dr, Ste 600
McLean, VA 22102
(703) 821-8955, ext 248 (voice)
(703) 821-2098 (fax)

SUDDEN INFANT DEATH SYNDROME

National Sudden Infant Death Syndrome Resource Center
8201 Greensboro Dr, Ste 600
McLean, VA 22102-3810
(703) 821-8955 (voice)
(703) 821-2098 (fax)

VISUAL IMPAIRMENTS

National Eye Institute
Bldg 31, Rm 6A32
31 Center Dr, MSC 2510
Bethesda, MD 20892-2510
(301) 496-5248 (voice)
(301) 402-1065 (fax)

OTHER FEDERAL RESOURCES

These federal resources can provide information on programs, services and related laws and regulations.

Administration on Developmental Disabilities
US Dept of Health and Human Services
HHH Bldg, Rm 329D
200 Independence Ave SW
Washington, DC 20201
(202) 690-6590 (voice)
(202) 690-6415 (TTY)
(202) 690-6904 (fax)
Develops and administers programs protecting rights and promoting independence, productivity and inclusion; funds state grants, the Protection and Advocacy programs, University Affiliated Programs and national projects.

Division of Birth Defects and Developmental Disabilities
National Ctr for Environmental Health
Centers for Disease Control and Prevention
4770 Buford Hwy NE
Mailstop F-45
Atlanta, GA 30341-3724
(404) 488-7150 (voice)
(404) 488-7156 (fax)
Provides assistance to community organizations to implement prevention programs.

Indian Health Service
Parklawn Bldg, Rm 2014
5600 Fishers Ln
Rockville, MD 20857
(301) 443-3593 (voice)
(301) 443-0507 (fax)
Counseling and referrals to American Indian and Alaska Native families with children with disabilities.

National Library Service for the Blind and Physically Handicapped
Library of Congress
1291 Taylor St NW
Washington, DC 20542
(202) 707-5100 (voice)
(202) 707-0744 (TTY)
(202) 707-0712 (fax)
Provides Braille and recorded books and magazines on free loan to anyone who cannot read standard print because of visual or physical disabilities.

Office of Fair Housing and Equal Opportunity
Dept of Housing and Urban Development
Office of Fair Housing and Equal Opportunity
820 1st St NE, Ste 450
Washington, DC 20002
(202) 275-0848 (voice)
(202) 275-0772 (TTY)
(202) 275-0779 (fax)
Provides information and handles complaints about discrimination in housing.

Office of Special Education and Rehabilitative Services (OSERS)
US Dept of Education
Switzer Bldg
330 C St SW
Washington, DC 20202
(202) 205-8723 (voice)
(202) 205-8241 (TTY)
(202) 205-9252 (fax)
Supports educational programs for children with special needs, rehabilitation and research.

President's Committee on Employment of People with Disabilities
1331 F St NW, 3rd Fl
Washington, DC 20004
(202) 376-6200 (voice)
(202) 376-6205 (TTY)
(202) 376-6219 (fax)
Publishes and distributes free material on employment of people with disabilities, independent living, the Rehabilitation Act and job accommodation and placement.

President's Committee on Mental Retardation
Wilbur J Cohen Bldg, Rm 5325
330 Independence Ave SW
Washington, DC 20201
(202) 619-0634 (voice)
(202) 205-9519 (fax)
Advises the administration on providing services for people with mental retardation and on ways to prevent this disability. Publishes annual reports, bibliographies, conference reports and information on related topics.

Senate Subcommittee on Disability Policy
113 Hart Senate Office Bldg
Washington, DC 20510
(202) 224-6265 (voice)
(202) 224-3457 (TTY)
(202) 228-2923 (fax)
Has legislative jurisdiction over the Americans with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA), Rehabilitation Act, Developmental Disabilities Act and Technology-Related Assistance for Individuals with Disabilities (TECH) Act.

Social Security Administration
6401 Security Blvd
Baltimore, MD 21235
(800) 772-1213 (voice hotline)
(800) 325-0778 (TTY hotline)
(410) 965-7700 (voice)
(410) 965-0695 (fax)
Provides information about the Social Security and Supplemental Security Income (SSI) programs, disability benefits and entitlement to Medicare.

The Events That Make a Difference

Tampa, FL
March 10-12
Florida State Fair Expo Park
Career Fair Friday March 10 only

Edison, NJ
June 16-18
Raritan Center Expo Hall

Rosemont, IL
August 11-13
(Chicago)
Rosemont Convention Center

Anaheim, CA
April 21-23
Anaheim Convention Center

San Mateo, CA
September 29-October 1
(San Francisco Bay Area)
San Mateo Expo Center

95 ABILITIES EXPO

Attend

- **Make new friends, enjoy sports demos and special events...have fun!**
- **Discover new products, try and buy what you need!**

Attend

The Number One Show of Products and Services for People with Disabilities

Exhibits Showcase New Products

200 Exhibits: Vans, Lifts, Wheelchairs, Exercise, Computers, Wheelchair Scooters, Clothing, Daily Living Aids, Personal Care Products, Toys and more!

FREE Daily Workshops and Sports Demos

Learn the latest sports medicine techniques for athletes of all ages.

Computer Center Can Assist You

Learn about the latest in adapted computer and communication technology. Hands on demonstrations, free computer seminars.

Sponsored by local chapters of

ABILITIES EXPO is a must attend event for all ages, families, seniors, health care providers, educators and rehabilitation professionals. For more information please call (203) 256-4700 ext. 131

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Address _____

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95 Abilities Show

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The free 1995 NCM Consumer Products AfterTherapy™ Catalog features hundreds of products for independent living. The Catalog features products that allow for dressing and eating without assistance and to bathe more safely. Also included are products that will assist in exercise therapy and help improve communication. You can now conveniently order any of these products directly from the North Coast NCM Consumer Products AfterTherapy™ Catalog.

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Address _____

City State Zip _____

Area Code Phone _____

NCM Consumer Products Division
PO Box 6070
San Jose, CA 95150-6070

Circle # 68

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Montage®

Comfortable, fun and safe cycling for all ages and abilities

The Montage® by Just Two Bikes, Inc. joins cycling partners together in a relaxed, side-by-side position, eliminating balance concerns and allowing each rider an excellent view of the road and scenery.

The adjustable seating positions accomodate riders of different heights. Either partner may steer, and each rider has a separate drivetrain so they may pedal at their own cadence. Stores vertically to save space and allow easy maintenence.

Ideal for visually or physically challenged riders.

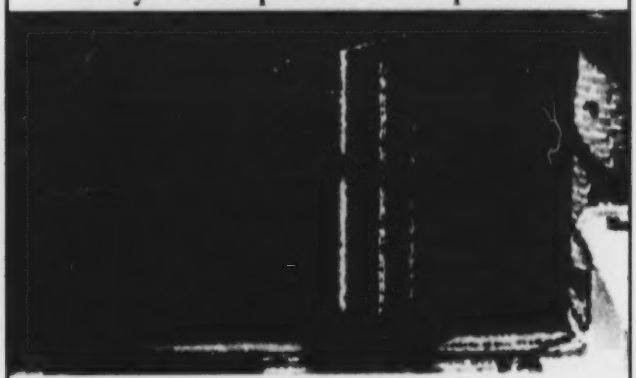
Contact JTB for details and a video brochure:
phone: 1-800-499-1548 fax: 1-612-426-1548
e-mail: 74771.2737@compuserve.com
4821 Washington Avenue, White Bear Lake, MN 55110

Circle # 140

For people with disabilities,

WE CAN

turn your computer into an open door.



A door opening to new opportunities — at work, at school and at home. Thanks to IBM technology, persons with vision, mobility, speech/hearing or attention/memory disabilities can do things once never thought possible. Like compete in the workplace and support families. Live independently of others. Find out more by calling 1-800-426-4832 (VOICE); 1-800-426-3333 (TDD); in Canada, 1-800-465-7999.

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Circle # 92

Exceptional Programs For Exceptional Children.

At St. Coletta Schools we believe life is what happens today. Our goal is to provide the best possible life experience for your exceptional child. Students here are not only preparing for tomorrow, they are living quality lives everyday. Founded in 1947, St. Coletta Schools offer a wide range of programs for children with mild to severe developmental disabilities. Twelve-month residential and day programs for ages 6-22.

- Extensive Vocational Training
- Functional Academics
- Community Skills Training
- Daily Living & Social Skills
- Adapted Phys. Ed. & Recreation Activity Program
- Special Olympics
- Behavior Management
- Physical & Occupational Therapy
- Speech Therapy
- Music, Art & Computers
- Prader-Willi Program

St. Coletta's
OF MASSACHUSETTS
John W. Shyne, Jr., President

Cardinal Cushing School & Training Center
400 Washington Street, Hanover, MA 02339
Braintree St. Coletta Day School
85 Washington Street, Braintree, MA 02184
Contact: Lynne Goyuk
Tel: (617) 826-6371
Fax:(617) 826-6474
Sponsored by
The Sisters of St. Francis of Assisi of Milwaukee, WI

Circle # 162

Superior Quality
Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day, residential and vocational programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources. Few other programs can offer such an open and productive relationship.

There are five programs for women (from semi-independent to supportive) including one specifically designed for mature women. **A new community-based program for men has been added.** The program offers training in home care and maintenance, budgeting, household management, and participation in an established vocational program.

All Programs Offer These Advantages

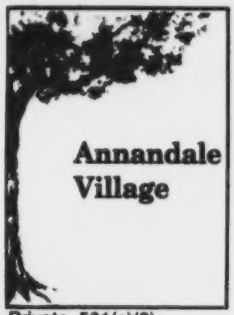
- Life skills and vocational training.
- Employment opportunities at Martha Lloyd and in the Troy community.
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation.
- A caring professional staff experienced in working with developmental disabilities.
- Our interdisciplinary team approach assures continuity and consistency in individual planning.
- Unique leisure and recreational experiences in a rural community setting.
- Excellent health care provided by on-staff health professionals and a community medical center.
- Annual fees among the lowest in the nation.

MARTHA LLOYD COMMUNITY SERVICES

For Information Call

(717) 297-2185

or write: Martha Lloyd Community Services
190 West Main St., Troy, PA 16947



Private, 501(c)(3)
Nonprofit Community

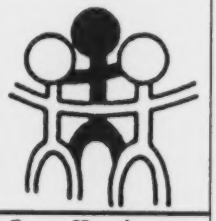
"THEIR COMMUNITY...WITH OUR HELP" Residential, day, and evening programs and services for adults with developmental disabilities.
- Paid Vocational Training
- Visual and Performing Arts
- Daily Living/Life Skills
- Therapeutic Recreation
- Case Management
- Health Services
- Off-Campus Activities
- 125-Acre Wooded Environment

Annandale at Suwanee, Inc.
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381

The ArborWay School

THE ARBORWAY SCHOOL
A 24 hour learning experience which provides individualized services for multihandicapped students.
- 1:2 staff to student ratio
- clinical consultants on staff
- recreational and leisure activities
- vocational training & on-site work
- 12 month program
- ages 6 through 22

Contact: Carolyn MacRae, Executive Director
Arborway School
147 South Huntington Avenue
Boston, MA 02130
617-232-1710



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33rd Year

A VERY SPECIAL CAMP FOR SPECIAL NEEDS CAMPERS
A co-ed residential camp for the:
- Learning Disabled, ADD.
- Neurologically Impaired.
- Mild-Moderate MR.

Located in beautiful High Falls in the Catskill Mts. of NY state.
2, 4, 8 wk. sessions. Highly qualified staff. 33rd year. Free brochure.

Contact: Bruria K. Falik, Ph.D.
Camp Huntington
56 Bruceville Road
High Falls, NY 12440
(914) 687-7840

CHILDREN'S CARE HOSPITAL & SCHOOL

CHILDREN'S CARE HOSPITAL & SCHOOL *(formerly Crippled Children's Hospital & School)* is a private, nonprofit facility serving over 1000 children with disabilities and their families each year. CCHS offers individualized, family-centered programs through day school, outpatient, outreach, or residential services.

Contact: Nathan Anderson
Children's Care Hospital & School
2501 West 26th Street
Sioux Falls, SD 57105-2498
(605) 336-1840 or (800) 584-9294

A point of light

CHILEDA HABILITATION INSTITUTE Educators for youths with developmental disabilities. Residential treatment center provides complete training & intensive therapy for children with severe mental & physical disabilities, closed head injuries & challenging behaviors. Estab. 1973.
- Intensive
- Progressive
- Specialized

Chileda Habilitation Institute
1020 Mississippi Street
LaCrosse, WI 54601
(608)782-6480 / (608)782-6481 (Fax)

"MAXIMIZING INDIVIDUAL POTENTIAL" Community-based, positive learning environment for difficult-to-place children, adolescents and young adults with MR, autism, communication disorders, and challenging behaviors. A program of the Protestant Guild for Human Services, Inc.
- 12-mo. day/residential programs.
- 10 miles west of Boston.

Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000

OAK HILL SCHOOL
100 Years of Compassion
Exceptional people deserve exceptional care. CIB/Oak Hill School enters its second century of compassionate care and ground-breaking education for children and adults with severe developmental disabilities.
- Residential living
- Day and vocational programs
- Loving, supportive environment
- Dedicated, highly-qualified staff

CIB/Oak Hill
120 Holcomb St.
Hartford, CT 06112
(203) 242-2274

YAI

Exciting Camping Opportunity for Children with Developmental and Learning Disabilities from: YAI (Young Adult Institute) We proudly announce openings for the summer of 1995 to **MAINSTREAM AT CAMP(MAC).** A nationally recognized award-winning (*Exceptional Parent* commendation '93) residential camp program for children and young adults. One to four week sessions.

Iran Buckler
Young Adult Institute
320 West 13th Street
New York, NY 10014-1206
(212) 645-1616/fax (212) 645-3869

Berkshire Meadows

Nestled in the serene beauty of western Massachusetts' Berkshire Hills, Berkshire Meadows' carefully designed fifteen-acre campus offers a comprehensive, integrated year-round residential program for children and adolescents who are severely developmentally delayed and may be multiply disabled.

Like other children all over the world, residents of Berkshire Meadows attend "school" (our Learning Center) five days a week. Each follows his or her own curriculum, designed to respond to individual needs: physical development, cognitive development (based on Piaget), the use of basic living skills. Our program for young adults also includes Applied Academics: techniques such as the use of money, and basic computing. And as a corollary to the Total Communication techniques we apply throughout our program, all students participate in Augmentative Communication training, where individual methods of communication are developed.

The young people live in spacious one-story homes, each with its own lounge, visiting area , kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

Each resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

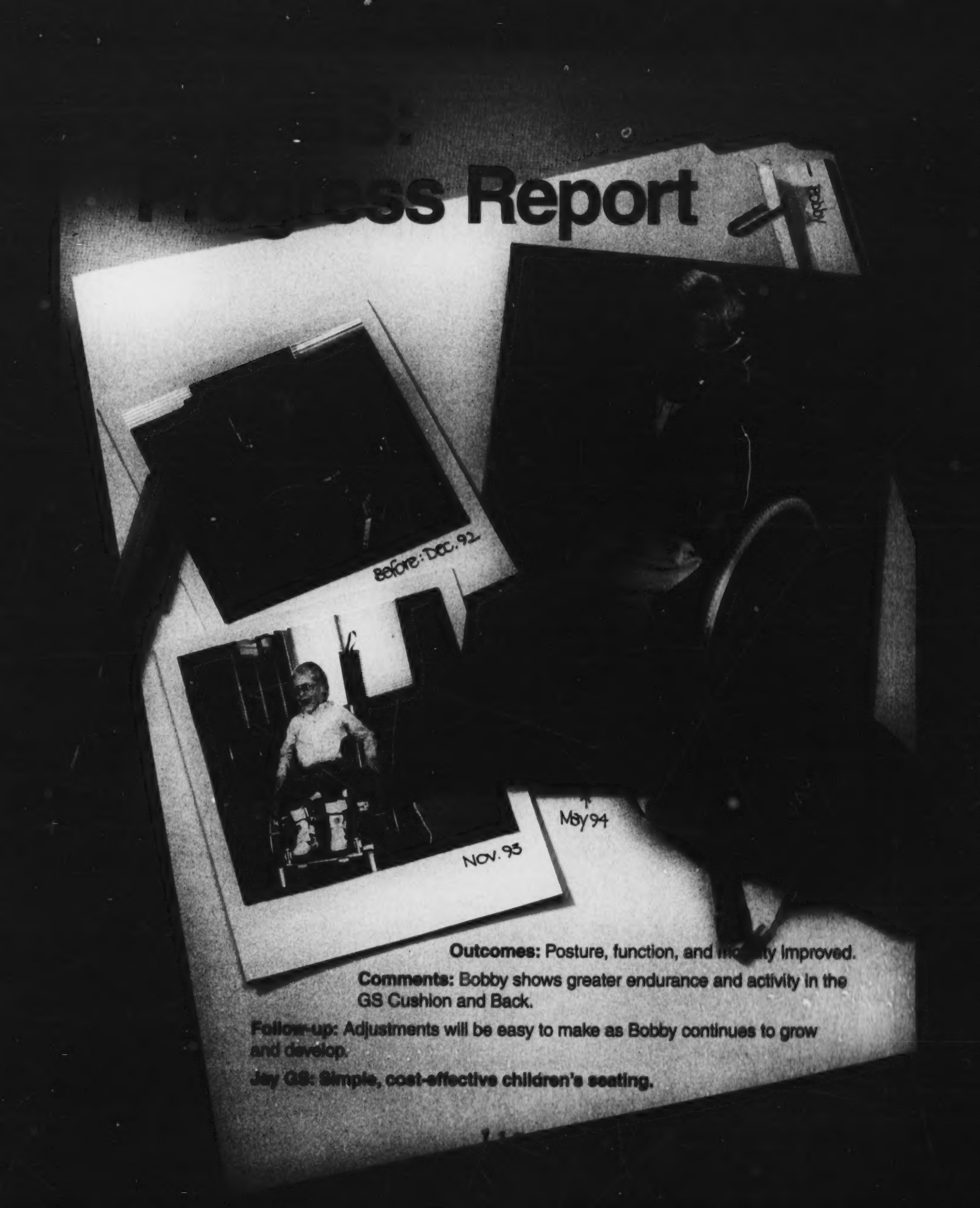
Weekends and holidays are for fun. We take full advantage of the loveliness of our natural surroundings, and of the receptive friendliness and extensive activities of local communities.

Our intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523

Circle # 10

ss Report



Outcomes: Posture, function, and [illegible]y improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.

PROFESSIONAL ORGANIZATIONS

Membership in many professional organizations is often limited to professionals working in specific fields. However, many organizations offer information and resources to non-members. If interested in specific organizations, please contact them for further details.

This directory was compiled with the help of NICHCY (National Information Center for Children and Youth with Disabilities), 1875 Connecticut Ave., NW, Washington, DC 20009, (800) 695-0285 (V/TTY), (202) 884-8441 (fax).

Academy of DENTISTRY for Persons with Disabilities
211 E Chicago Ave, Ste 948
Chicago, IL 60611
Assists dentists, dental hygienists, students and other dental care providers in acquiring and maintaining skills and knowledge to provide comprehensive dental care to people with disabilities.

American Academy of PEDIATRIC DENTISTRY
211 E Chicago Ave, Ste 700
Chicago, IL 60611
(312) 337-2169 (voice)
(312) 337-6329 (fax)
Represents 3,700 members in pediatric dentistry. Emphasizes three-part approach to caring for children: practice, teaching and research.

American Academy of PEDIATRICS
PO Box 927
Elk Grove Village, IL 60009
Represents 49,000 pediatricians. Dedicated to the health, safety and well-being of infants, children, adolescents and young adults. Committee on Children with Disabilities studies the role of pediatricians in the care of children with chronic illnesses and disabilities.

American Alliance for HEALTH, PHYSICAL EDUCATION, RECREATION and DANCE
1900 Association Dr
Reston, VA 22091
(703) 476-3400 (voice)
(703) 476-9527 (fax)
Concerned with improving physical education, sports, health and safety education, recreation and dance programs in schools and communities. Offers publications in planning, organizing and conducting programs for people with disabilities.

American ART THERAPY Association
1202 Allanson Rd
Mundelein, IL 60060
(708) 949-6064 (voice)
(708) 566-4580 (fax)
Approves graduate-level training programs in art therapy and registers professional therapists.

American Association for VOCATIONAL INSTRUCTIONAL MATERIALS
220 Smithonia Rd
Winterville, GA 30683
(800) 228-4689 (voice)
(706) 742-7005 (fax)
Publishes instructional books, videos and computer software on agriculture, home economics, and trade and industrial arts.

American Association of CHILDREN'S RESIDENTIAL CENTERS
1021 Prince St
Alexandria, VA 22314
(703) 838-7522 (voice)
(703) 684-5968 (fax)
Represents mental health facilities that meet required standards in therapeutic living, educational programs, group therapy and parent or family therapy for children with emotional problems. Provides technical assistance for new residential treatment center programs.

American Association on MENTAL RETARDATION
444 N Capital St NW, Ste 846
Washington, DC 20001
(800) 424-3688 (voice)
(202) 387-1968 (voice)
(202) 387-2193 (fax)
Seeks to improve services to people who have mental retardation. Offers professional workshops and consultations for training and technical assistance.

American Association of UNIVERSITY AFFILIATED PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES
8630 Fenton St, Ste 410
Silver Spring, MD 20910
(301) 588-8252 (voice)
(301) 588-3319 (TTY)
(301) 588-2842 (fax)
Central office of the 54 university affiliated programs (UAPs). UAPs offer training of professionals and para-professionals dealing with people with developmental disabilities; screening, evaluation, treatment, planning and educational programming; technical assistance to service agencies and dissemination of research findings.

American COUNSELING Association
5999 Stevenson Ave
Alexandria, VA 22304
(703) 823-6862 (voice)
(703) 823-0252 (fax)
Provides professional counselors, counselor educators and related human development specialists with programs and services for personal and professional growth. Accredits counselor education programs.

American DANCE THERAPY Association
2000 Century Plaza, Ste 108
Columbia, MD 21044
(410) 997-4040 (voice)
(410) 997-4048 (fax)
Approves educational programs in dance/movement therapy and registers professional therapists. Provides local professional contacts, free information on educational programs and guidelines for dance/movement therapy training and internships.

American HORTICULTURAL THERAPY Association
362A Christopher Ave
Gaithersburg, MD 20879
(301) 948-3010 (voice)
(301) 869-2397 (fax)
Consults to institutions interested in establishing horticultural therapy programs. Registers professional therapists and sponsors national and regional workshops.

American MEDICAL Association
515 N Dearborn St
Chicago, IL 60610
(800) 262-3211 (voice)
(312) 464-5000 (voice)
(312) 464-4184 (fax)
Represents physicians, academicians, medical students and representatives of organized medicine.

American MENTAL HEALTH COUNSELORS Association
5999 Stevenson Ave
Alexandria, VA 22304
(703) 823-9800 (voice)
(703) 823-6862 (TTY)
(703) 823-0252 (fax)
A division of the American Association for Counseling and Development. Provides support to professional mental health counselors. Sets service training standards and advocates on legislative issues.

American Network of COMMUNITY OPTIONS AND RESOURCES
4200 Evergreen Ln, Ste 315
Annandale, VA 22003
(703) 642-6614 (voice)
(703) 642-0497 (fax)
Represents about 500 private service provider companies for people with developmental disabilities, mental illness and other disabilities. Provides training and educational opportunities for its members.

American NURSES Association
600 Maryland Ave SW, Ste 100W
Washington, DC 20024-2571
(202) 651-7000 (voice)
(202) 651-7001 (fax)
Represents more than 210,000 registered nurses. Advances nursing by upholding high standards of practice, promoting the economic and general welfare of nurses in the workplace and projecting a positive and realistic view of nursing. Lobbies on health care issues.

PROFESSIONAL ORGANIZATIONS

American OCCUPATIONAL THERAPY Association
4720 Montgomery Ln
PO Box 31220
Bethesda, MD 20824
(800) 377-8555 (TTY)
(301) 948-9626 (voice)
(301) 652-7711 (fax)
Accredits educational programs, certifies practitioners and advocates on programs related to national health care issues. Distributes professional information packets on many subjects.

American ORTHOTIC and PROSTHETIC Association
1650 King St, #500
Alexandria, VA 22314
(703) 836-7116 (voice)
(703) 836-0838 (fax)
Represents manufacturers of orthotic and prosthetic devices and facilities providing prosthetic patient care. Provides a list of schools offering a curriculum in orthotics and/or prosthetics.

American PHYSICAL THERAPY Association
1111 N Fairfax St
Alexandria, VA 22314
(800) 999-2782 (voice)
(703) 684-2782 (voice)
(703) 684-7343 (fax)
Accredits academic programs in physical therapy, assists in composing state certification exams and offers educational courses and workshops. Refers people with disabilities to physical therapy facilities.

American PSYCHOLOGICAL Association
750 First St NE
Washington, DC 20002
(800) 336-4980 (voice)
(202) 336-5500 (voice)
Works to advance psychology as a science, a profession and a means of promoting human welfare. Promotes policy, research and standards of ethical conduct and education.

American REHABILITATION COUNSELING Association
5999 Stevenson Ave
Alexandria, VA 22304
(703) 823-9800 (voice)
(703) 823-0252 (fax)
Division of the American Counseling Association (ACA). Seeks to improve rehabilitation counseling services to people with disabilities. Supports and participates in ACA's accreditation.

American SCHOOL COUNSELOR Association
5999 Stevenson Ave
Alexandria, VA 22304
(703) 823-9800 (voice)
(703) 823-6862 (TTY)
(703) 823-0252 (fax)
Provides support to counselors, counseling and guidance directors, supervisors, administrators and counselor educators.

American SCHOOL HEALTH Association
7263 State Rt 43
PO Box 708
Kent, OH 44240
(216) 678-1601 (voice)
(216) 678-4526 (fax)
Promotes comprehensive school health programs. Offers free publication catalog.

American SPEECH-LANGUAGE-HEARING Association
10801 Rockville Pike
Rockville, MD 20852
(800) 638-8255 (V/TTY)
(301) 897-5700 (V/TTY)
(301) 571-0457 (fax)
Certifying body for professionals in speech, language and hearing therapy. Accredits graduate, clinic and hospital programs in speech-language pathology and audiology. Provides free information, referrals and consumer-oriented publications through toll-free (800) phone number.

Association for CHILDHOOD EDUCATION International
11501 Georgia Ave, Ste 315
Wheaton, MD 20902
(800) 423-3563 (voice)
(301) 942-2443 (voice)
(301) 942-3012 (fax)
Concerned with development, growth and education from infancy through early adolescence. Sponsors annual conference. Offers about 100 books, pamphlets, videos and audiotapes through publication catalog.

Association for DRIVER EDUCATORS for the Disabled
PO Box 49
Edgerton, WI 53534
(608) 884-8833 (voice)
(608) 884-4851 (fax)
Seeks to improve driver education and evaluation for people with disabilities. Provides information on teaching techniques, assessment methods and technological developments.

Association of Schools of ALLIED HEALTH Professionals
1730 M St NW, Ste 500
Washington, DC 20036
(202) 293-4848 (voice)
(202) 293-4852 (fax)
Represents health care professionals and educators in wide range of fields including corrective, occupational, physical and recreational therapies. Provides information on allied health, innovative projects and individual expertise. Sponsors annual conference, leadership workshops, fellowships and a world congress.

Association of Specialized and Cooperative LIBRARY Agencies
American Library Association
50 E Huron St
Chicago, IL 60611
(800) 545-2433 (voice)
(312) 944-6780 (voice)
(312) 944-7298 (TTY)
(312) 280-3255 (fax)
Represents librarians serving communities and special populations, including people with physical and mental disabilities. Provides printed information to libraries interested in developing services for people who are blind or who have mental retardation.

Association on HIGHER EDUCATION and Disability
PO Box 21192
Columbus, OH 43221
(614) 488-4972 (V/TTY)
(614) 488-1174 (fax)
Committed to full participation in higher education for people with disabilities. Sponsors annual conference and publishes material for service providers. Maintains resume databank of people with disabilities seeking employment.

Council for EXCEPTIONAL CHILDREN
1920 Association Dr
Reston, VA 22091
(703) 620-3660 (voice)
(703) 264-9494 (fax)
Monitors and analyzes policies concerning children and youth with disabilities and children and youth who are gifted. Offers publications on special education, disability awareness, child abuse, recreation, parent-professional cooperation, career and vocational education and public policy.

National Association for MUSIC THERAPY
8455 Colesville Rd
Silver Spring, MD 20910
(301) 589-3300 (voice)
(301) 589-5175 (fax)
Approves university curricula for music therapy programs, approves clinical facilities for training music therapists, certifies and registers professionals and provides technical assistance to researchers.

National Association for PERINATAL ADDICTION Research and Education
200 N Michigan Ave, 3rd Fl
Chicago, IL 60601
(312) 541-1272 (voice)
(312) 541-1271 (fax)
Addresses perinatal addiction and the long-term outlook for children exposed in utero to illicit drugs. Provides national network for exchange of information, provides education, coordinates research and translates current research into public education programs and public health policy.

National Association for the EDUCATION OF YOUNG CHILDREN
1509 16th St NW
Washington, DC 20036-1426
(800) 424-2460 (voice)
(202) 232-8777 (voice)
(202) 328-1846 (fax)
Represents 90,000 early childhood professionals and others dedicated to improving the quality of early childhood education programs for children birth through age eight. Accredits early childhood programs. Offers books, brochures, posters and videos.

National Association of DEVELOPMENTAL DISABILITIES COUNCILS
1234 Massachusetts Ave NW, Ste 103
Washington, DC 20005
(202) 347-1234 (voice)
(202) 347-4723 (fax)
Promotes development of public policy for community integration and services to people with developmental disabilities through developmental disabilities councils in states and territories.

National Association of MEDICAL EQUIPMENT SERVICES
625 Slaters Ln
Alexandria, VA 22314-1176
(703) 836-6263 (voice)
(703) 836-6730 (fax)
Represents more than 2,000 home medical equipment and rehabilitation technology suppliers. Promotes access to quality home medical equipment services and rehabilitation/assistive technology.

National Association of PRIVATE SCHOOLS for Exceptional Children
1522 K St NW, Ste 1032
Washington, DC 20005
(202) 408-3338 (voice)
(202) 408-3340 (fax)
Promotes the role of private special education. Serves as national voice regarding policies that affect children and youth with disabilities.

National Association of REHABILITATION FACILITIES
1910 Association Dr
Reston, VA 22091
(800) 368-3513 (voice)
(703) 648-9300 (voice)
(703) 648-0346 (fax)
Advocates on behalf of rehabilitation services to people with disabilities. Provides field services and technical assistance to members and others. Conducts research, sponsors educational forums and develops policy.

National Association of SOCIAL WORKERS
750 First St NE, Ste 700
Washington, DC 20002
(800) 638-8799 (voice)
(202) 336-8310 (fax)
Proposes and promotes sound public policies and programs aimed at meeting human needs and improving quality of life.

National Association of STATE DIRECTORS OF DEVELOPMENTAL DISABILITIES SERVICES
113 Oronoco St
Alexandria, VA 22314
(703) 683-4202 (voice)
Facilitates exchange of information among its 53 state/territorial mental retardation program directors on providing care and treatment for people with mental retardation.

National Association of STATE DIRECTORS OF SPECIAL EDUCATION
1800 Diagonal Rd, Ste 320
Alexandria, VA 22314
(703) 519-3800 (voice)
(703) 519-7008 (TTY)
(703) 519-3808 (fax)
Represents personnel from state education agencies who have legal responsibility for the administration and supervision of special education programs in public schools. Assists local, state and national communities in promoting and enhancing special education.

National EDUCATION Association
1201 16th St NW
Washington, DC 20036
(202) 833-4000 (voice)
(202) 822-7767 (fax)
Informs its members about the Individuals with Disabilities Education Act (IDEA). Members receive a teacher's guide to IDEA and information on training to help regular teachers integrate students with and without disabilities.

National THERAPEUTIC RECREATION Society
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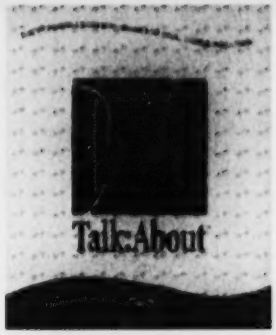

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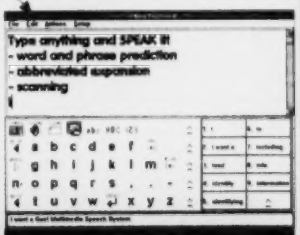

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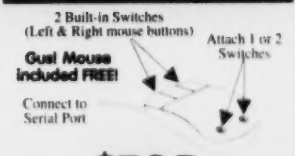

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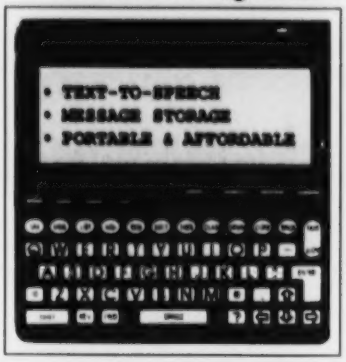

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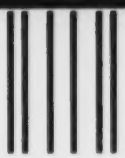

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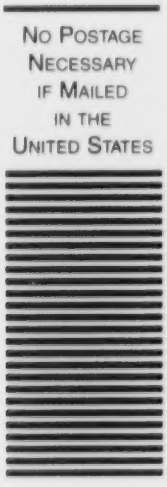

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1994 SEARCH AND RESPOND INDEX

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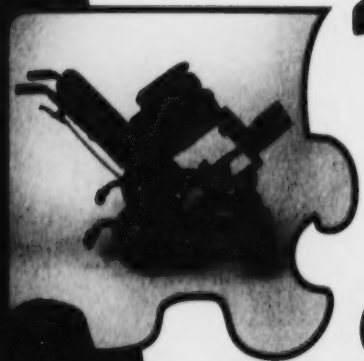
Darrow syndrome	Jul	
Daycare	Apr	
Deafness, motor impairments and	Dec	
DiGeorge syndrome	Jun	Aug
Disabilities, Multiple, Unsure about future	Sep	
Disabilities, Parents with	(Nov/Dec 93)	Mar
Disabilities, Single parent with	(Sep 93)	Apr
Disabilities, Severe	Sep	
Disabilities, Three children with	Feb	May, Jun
Disability awareness in public schools	Oct	
Down syndrome and blind	Nov	
Down syndrome and feeling "different"	Jun	Aug
Down syndrome and non-verbal	Oct	Dec
Down syndrome, Two children with	Apr	
Drooling	Jul	
Dystonia, Generalized	Mar	
Early myoclonic encephalopathy syndrome, Nonoxynol-9 spermicide and	(Oct 93)	Feb
Encephalocele and Meckel syndrome	Apr	
Epidermal nevus syndrome, lipomas and	Apr	
Failure to thrive, Non-organic	Nov	
Fiber-type disproportion, Congenital	Dec	
G-Tube	(Oct 93)	Feb
G-Tube with internal disk	May	
Guillain-Barre syndrome, Chronic	Dec	
Herpes encephalitis, neonatal	Sept	
Holoprosencephaly, Semilobar	(Nov/Dec 93)	Feb
Hypotonia, Benign congenital	Apr	Aug
Inclusive school districts (New England)	Mar	Jun
Inclusion, Feeling "different"	Jun	Aug
Increased activity, Episodes of	Jul	
Infantile spasms	Aug	
Insurance	Nov	
Ischemic strokes	Apr	Jul
Jacobsen's syndrome	Mar	
Johanson-Blizzard syndrome	Sep	
Kabuki makeup syndrome	Aug	
Klinefelter syndrome/48,XXXY	Oct	
Landau-Kleffner syndrome/Asperger's syndrome	(Nov/Dec 93)	Mar
Langer-Giedion syndrome	Feb	
Learning disabilities, Dealing with the system	Feb	
Learning disabilities, Parents with	Mar	
Leber's congenital amaurosis	(Nov/Dec 93)	Mar
Lennox-Gastaut syndrome	Mar	Jun
Lipomas, Epidermal nevus syndrome and	Apr	
Lipomyelomeningocele	Aug	
Loud noises in public	Dec	
Macroglossia	Mar	
Meckel syndrome, Encephalocele and	Apr	
Monsomy 5p/Trisomy 4p	Sep	
Motor impairments, Deafness and	Dec	
Multiple disabilities, Unsure about future	Sep	
Muscular dystrophy, Autism/PDD and	Feb	
Myotubular myopathy, X-linked	Mar	
Nail-patella syndrome	Apr	Sep
Necrotizing enterocolitis	Jul	
Neurological disorder, Progressive	Sep	
Nonoxynol-9 spermicide, Early myoclonic encephalopathy syndrome and	(Oct 93)	Feb
Norrie disease and cataplexy	Apr	
Obsessive-compulsive disorder	Jul	Oct
Panic attacks?	Jun	
Parent, Single, with disabilities	(Sep 93)	Apr
Parents, adoptive	Aug	Oct
Parents with disabilities	(Nov/Dec 93)	Feb
Parents with learning disability	Mar	
Pen pal for sibling	Feb	
Personal attendant, College with	Feb	Apr, May
Pfeiffer syndrome	Nov	
Prader-Willi syndrome with normal DNA test	May	Jul, Aug
PTO activities	Feb	
Puberty, Autism and	(Sep 93)	Feb
Rasmussen syndrome	Feb	May
Recreation, Therapeutic	Dec	
Rhizotomy	May	Sep
Ring chromosome 22	Jun	
Ritalin, Autism and	May	Jul
Robinow syndrome	Jun	
School bus, Riding the	Feb	May 42
Scoliosis	Jun	
Seizures	Jul	
Seizures, Bleeding during	Apr	Jul
Seizures, Uncontrollable	Feb	
Semilobar holoprosencephaly	(Nov/Dec 93)	Feb
Service dogs	Feb	
Shaking, Severe	Jul	
Shoes, Wide	(Sep 93)	Feb, May
Single parent with disabilities	(Sep 93)	Apr
Skeletal anomalies	Jun	Sep
Spastic paraparesis	Apr	
Spina Bifida, Two children with	Aug	Oct
Stepparenting	Nov	
Strokes, Ischemic	Apr	Jul
Teeth grinding	Jun	Aug
Therapeutic recreation	Dec	
Transporting two non-ambulatory children	Feb	Jun
Trisomy 4p/Monsomy 5p	Sep	
Trisomy 8, Partial	Jul	
Trisomy 19Q	Feb	
Twins, Identical, One with a disability	Oct	Dec
Umbilical cord sampling	May	
Undiagnosed	(Nov/Dec 93)	Mar, Apr
Undiagnosed	Aug	Nov
Undiagnosed	Sep	
Ventilator, Cart for	Mar	
Ventilator dependence	Aug	Nov
Voice amplification equipment	Oct	
Vomiting problem	Jun	Oct
Werdnig-Hoffman disease	Sep	Nov
Werdnig-Hoffman disease?	Mar	

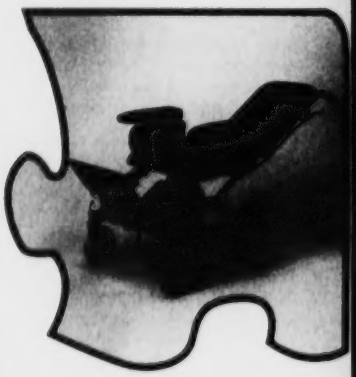
Freedom Designs, Inc.

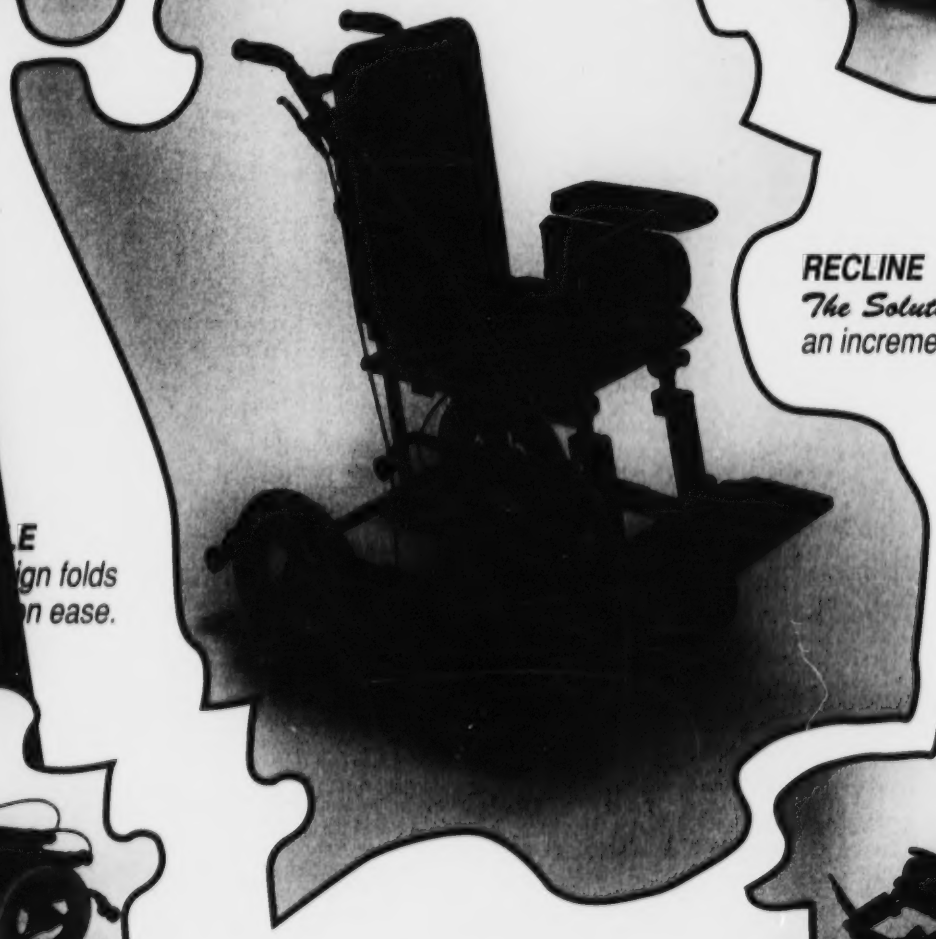
Not just another piece of the puzzle.

The Solution



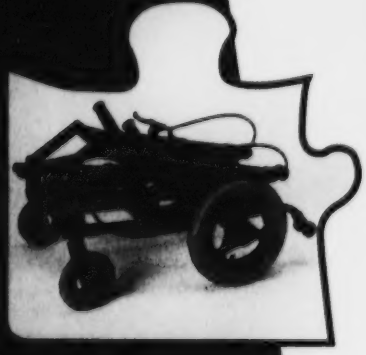
TILT IN SPACE
Our tilt in space feature is easy to operate.

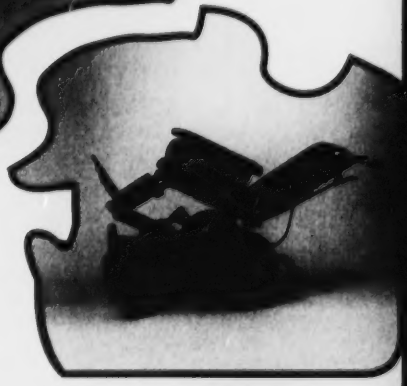




RECLINE
The Solution *offers an incremental recline.*

E
ign folds
n ease.





TILT AND RECLINE
The frame can be reclined and tilted simultaneously.

om Designs, Inc. 2241 Madera Road ◆ Simi Valley, CA 93065
one (800) 331-8551 ◆ (805) 582-0077 ◆ Fax (805) 582-1509

FREEDOM DESIGNS INCORPORATED

Circle # 168

Product & Service Directory

The listings in this directory were purchased by the listed companies or organizations. Representatives from each company selected the category or categories under which they are listed.

Augmentative Communications Equipment

Consultants for Comm Technology
508 Bellevue Terr
Pittsburgh, PA 15202
(412) 761-6062
(412) 761-7336 (fax)

Don Johnston Incorporated
1000 N Rand Rd, Bldg 115
Wauconda, IL 60048
(800) 999-4660/(708) 526-2682
(708) 526-4177 (fax)
Circle #141
See our ad on page 112.

GMR Labs
1030 E El Camino Real, #308
Sunnyvale, CA 94087
(408) 985-7200
(408) 243-3731 (fax)
Circle #13
See our ad on page 54.

Gus Communications, Inc.
PO Box 4362
Blaine, WA 98231-4362
(604) 279-0110
(604) 279-8474 (fax)
Circle #36
See our ad on page 112.

IBM Special Needs Systems
1000 NW 51st St
Boca Raton, FL 33432
(800) 426-4832
(407) 982-6059 (fax)
Circle #92
See our ad on page 104.

Imaginart Communication Products
307 Arizona St
Bisbee, AZ 85603
(800) 828-1376
(602) 432-5134 (fax)
Circle #145
See our ad on page 90.

Jesana Ltd.
PO Box 17
Irvington, NY 10533
(800) 443-4728
(914) 591-4320 (fax)
Circle #178
See our ad on page 97.

LC Technologies
9455 Silver King Ct
Fairfax, VA 22031
(703) 385-7133
(703) 385-7137 (fax)
Circle #163
See our ad on page 96.

Passy-Muir, Inc.
4521 Campus Dr, Ste 273
Irvine, CA 92715
(714) 833-8255
(714) 833-8299 (fax)

Prentke Romich Company
1022 Heyl Rd
Wooster, OH 44691
(800) 262-1933
(216) 263-4829 (fax)
Circle #59
See our ad on page 52.

Sentient Systems Technology Inc.
2100 Warburton St
Pittsburgh, PA 15203-1942
(800) 344-1778
(412) 381-5241 (fax)
Circle #161
See our ad on page 84.

Temasek Telephone, Inc.
21 Airport Blvd #G
SoSan Francisco, CA 94080
(415) 875-6666
(415) 875-7608 (fax)
Circle #121
See our ad on page 40.

Tiger Communication System, Inc.
155 E Broad St, Ste 325
Rochester, NY 14604
(800) 724-7301
(716) 454-3631 (fax)
Circle #40
See our ad on page 116.

WorkLink
2452 Armstrong St
Livermore, CA 94550
(510) 606-3763
(510) 606-3769 (fax)

Bathroom Equipment

AccessAble Environments & Products
111 Cedar St
New Rochelle, NY 10801
(800) 285-2525
(914) 632-1357 (fax)
Circle #103
See our ad on page 74.

Adaptive Design Shop
12847 Pt Pleasant Dr
Fairfax, VA 22033
(703) 631-1585
Circle #32
See our ad on page 111.

American Standard (Pressalit)
One Centennial Ave
PO Box 6820
Piscataway, NJ 08855
(800) 524-9797 ext. 469
Circle #175
See our ad on page 45.

Barrier Free Lifts, Inc.
PO Box 4163
Manassas, VA 22110
(703) 361-6531
(703) 361-7861 (fax)
Circle #39
See our ad on page 44.

Clarke Health Care Products
PIIP/ICM Bldg
1003 International Dr
Oakdale, PA 15071-9223
(412) 695-2122
(412) 695-2922 (fax)

Columbia Medical Mfg. Corp.
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612
(310) 305-1718 (fax)
Circle #152
See our ads on pages 12 & 121.

H.D.I.S. Company, Inc.
1215 Dielman Industrial Ct
St. Louis, MO 63132
(800) 538-1036
(314) 997-0047 (fax)
Circle #15
See our insert on pages 67-70.

Lubidet USA, Inc.
950 S Cherry St, 506
Denver, CO 80222
(800) 582-4338/(303) 757-3031
(303) 757-3868 (fax)
Circle #117
See our ad on page 122.

NCM Consumer Products Division
PO Box 6070
San Jose, CA 95150
(800) 235-7054
(408) 277-6824 (fax)
Circle #68
See our ad on page 104.

Ortho-Kinetics, Inc.
W220 N 507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (fax)

Tumble Forms
744 W Michigan Ave
Jackson, MI 49203
(517) 789-3377
(517) 789-3333 (fax)
Circle #27
See our ad on back cover.

Bedding

Hard Manufacturing Co., Inc.
230 Grider St
Buffalo, NY 14215-3797
(800) USE-HARD/(716) 893-1800
(716) 896-2579 (fax)
Circle #44
See our ad on page 42.

Bicycles/Tricycles

Just Two Bikes, Inc.
4821 Washington Ave
White Bear Lake, MN 55110
(800) 499-1548
(612) 426-1548 (fax)
Circle #140
See our ad on page 104.

Rock N'Roll Cycles
PO Box 1558
Levelland, TX 79336
(800) 654-9664
(806) 894-9646 (fax)
Circle #171
See our ad on page 41.

Step'n Go Cycles
PO Box 180, Cedar Beach Rd
Charlotte, VT 05445
(800) 648-7335
(802) 425-2264, ext 254
(802) 425-3007 (fax)
Circle #125
See our ad on page 113.

Triaid
PO Box 1364
Cumberland, MD 21502
(800) 306-6777/(301) 759-3525
(301) 759-3525 (fax)
Circle #46
See our ad on page 72.

PRODUCT & SERVICE DIRECTORY

Clothes/Footware

eSpecials (Down Syndrome/PW)
PO Box 1177
Larkspur, CA 94977
(415) 924-7960
(415) 927-9043 (fax)

I-2 Kids Clothes
100 Springdale Rd A-3, Ste 164
Cherry Hill, NJ 08003
(609) 770-8474
(609) 427-9560 (fax)

Kotton & Koala
PO Box 178
Fort Jones, CA 96032
(916) 468-5475
(916) 468-5492 (fax)
Circle #18
See our ad on page 96.

M.J. Markell Shoe Co.
504 Saw Mill River Rd
Yonkers, NY 10701
(914) 963-2258
(914) 963-9293 (fax)
Circle #1
See our ad on page 56.

Moonbeams-Carol Nesper Studios
2026 Murray Hill Rd
Cleveland, OH 44106
(216) 721-4100
Circle #61
See our ad on page 39.

Special Clothes
PO Box 4220
Alexandria, VA 22303
(703) 683-7343
(703) 549-2640 (fax)

Wheelin' Wear (Children's Gloves)
PO Box 545
Cobourg, ON Canada K9A 4L3
(800) 488-2638
(905) 373-4941 (fax)

Computer Hardware & Accessories

Apple Computer, Inc.
20525 Mariani Ave, MS 36-SE
Cupertino, CA 95014
(800) 600-7808/(408) 996-1010
(800) 755-0601 (TTY)
(408) 362-5260 (fax)
See our ad on page 97.

Don Johnston Incorporated
1000 N Rand Rd, Bldg 115
Wauconda, IL 60048
(800) 999-4660/(708) 526-2682
(708) 526-4177 (fax)
Circle #142
See our ad on page 112.

EKEG Electronics Co. Ltd.
PO Box 46199, Station D
Vancouver, BC Canada V6J 5G5
(604) 273-4358
(604) 273-1148 (fax)

IBM Special Needs Systems
1000 NW 51st St
Boca Raton, FL 33432
(800) 426-4832
(407) 982-6059 (fax)
Circle #92
See our ad on page 104.

In Touch Systems
11 Westview Rd
Spring Valley, NY 10977
(800) 332-MAGIC
Circle #122
See our ad on page 56.

IntelliTools, Inc.
5221 Central Ave, #205
Richmond, CA 94804
(800) 879-6687/(510) 528-0670
(510) 528-2225 (fax)
Circle #42
See our ad on page 74.

Key Concepts
PO Box 21066
Charlotte, NC 28277
(800) 293-5090
Circle #50
See our ad on page 88.

RJ Cooper & Associates
24843 Del Prado, #283
Dana Point, CA 92629
(800) RJCOOPER
(714) 240-9785 (fax)
Circle #81
See our ad on page 79.

Synergy
68 Hale Rd
Walpole, MA 02032
(508) 668-7424
(508) 668-4134 (fax)

WorkLink
2452 Armstrong St
Livermore, CA 94550
(510) 606-3763
(510) 606-3769 (fax)

Driving Aids

Adaptive Driving Systems
21050 Superior St
Chatsworth, CA 91311
(818) 998-1026
(818) 882-0812 (fax)

Crow River Industries
14800 28th Ave N
Minneapolis, MN 55447
(800) 488-7688
(612) 557-8310 (fax)
Circle #120
See our ad on page 92.

GM Mobility Assistance Center
PO Box 9011
Detroit, MI 48202
(800) 323-9935
(800) 833-9935 (TTY)
(313) 974-4383 (fax)
Circle #94
See our ad on page 73.

Monmouth Vans, Access & Mobility
5105 Rte 33/34
Farmingdale, NJ 07727
(800) 221-0034
(908) 919-0256 (fax)

Ricon Corporation
12450 Montague St
Pacoima, CA 91331
(818) 899-7588
(818) 890-3354 (fax)
Circle #86
See our ad on page 53.

Educational Material

Attainment Company, Inc.
PO Box 930160
Verona, WI 53593-0160
(800) 327-4269
(800) 942-3865 (fax)

Bo Peep Productions Videotapes
PO Box 982
Eureka, MT 59917
(800) 532-0420
(406) 889-3225 (fax)

Don Johnston Incorporated
1000 N Rand Rd, Bldg 115
Wauconda, IL 60048
(800) 999-4660/(708) 526-2682
(708) 526-4177 (fax)
Circle #143
See our ad on page 112.

Gemma B. Publishing, Inc.
Box #713-740 Corydon Ave
Winnipeg, MB Canada R3M 0Y1
(204) 452-7566
(204) 475-9903 (fax)

Mind Play
160 W Ft Lowell
Tucson, AZ 85705
(800) 221-7911
(602) 888-7904 (fax)

River Tank Systems
PO Box 445
Exeter, RI 02822
(800) 808-8822
(401) 294-9510 (fax)
Circle #5
See our ad on page 55.

Voicing!
3857 Birch, Ste 194
Newport Beach, CA 92660
(714) 833-2710
(714) 833-1005 (fax)

Environmental Controls

Jesana Ltd.
PO Box 17
Irvington, NY 10533
(800) 443-4728
(914) 591-4320 (fax)
Circle #179
See our ad on page 97.

Finance/Estate Planning/Insurance

Abilities Plus Program
Special Auto & Home Insurance
PO Box 5198
Lutherville, MD 21094-9719
(800) 222-2788, Dept Q
Circle #137
See our ad on page 80.

Assoc for Special Kids (ASK)
107 W Hill St
Baltimore, MD 21230
(800) 832-0467/(410) 727-2118
(410) 727-3266 (fax)

Estate Planning (EPPD)
1200 Corporate Dr, Ste 330
Birmingham, AL 35242
(800) 448-1071
(800) 880-9327 (fax)
Circle #31
See our ad on page 95.

Food & Nutrition

Medical Innovations Corporation
12050 Lone Peak Pkwy
Draper, UT 84020
(801) 572-6800
(801) 572-6869 (fax)

Furniture

Columbia Medical Mfg. Corp.
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612
(310) 305-1718 (fax)
Circle #155
See our ads on pages 12 & 121.

Equipment Shop
PO Box 33
Bedford, MA 01730
(617) 275-7681
(617) 275-4094 (fax)
Circle #123
See our ad on page 88.

Headgear

Ortho-Kinetics, Inc.
W220 N 507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (fax)

Plum Enterprises, Inc.
9 Clyston Cir/PO Box 283
Worcester, PA 19490
(800) 321-PLUM
(215) 584-4151 (fax)
Circle #12
See our ad on page 3.

Hearing Aids/Equipment

Oticon, Inc.
29 Schoolhouse Rd
Somerset, NJ 08875
(800) 227-3921
(908) 560-0029 (fax)

Hobbies & Toys

The Dragonfly Toy Company
291 Yale Ave
Winnipeg MB Canada R3M 0L4
(204) 453-2222
(204) 453-2320 (fax)

InvoTek Corporation
700 W 20th St, ENRC
Fayetteville, AR 72701
(800) 576-6661
(501) 575-7446

River Tank Systems
PO Box 445
Exeter, RI 02822
(800) 808-8822
(401) 294-9510 (fax)
Circle #5
See our ad on page 55.

Rock N'Roll Cycles
PO Box 1558
Levelland, TX 79336
(800) 654-9664
(806) 894-9646 (fax)
Circle #172
See our ad on page 41.

Sony Electronics, Inc.
2 Van Riper Rd
Montvale, NJ 07645-0406
(201) 476-8160
(201) 476-8071 (fax)
Circle #104
See our ad on page 100.

Switch Kids, Inc.
8507 Rupp Farm Dr
West Chester, OH 45069
(513) 860-5475
(513) 860-5475 (fax)

TFH (USA)—Fun and Achievement
4537 Gibsonia Rd
Gibsonia, PA 15044
(412) 444-6400
(412) 444-6411 (fax)

Toys for Special Children
385 Warburton Ave
Hastings-on-Hudson, NY 10706
(800) 832-8697
Circle #160
See our ad on page 48.

Voicing!
3857 Birch, Ste 194
Newport Beach, CA 92660
(714) 833-2710
(714) 833-1005 (fax)

Home Adaptation/Design

AccessAble Environments & Product
111 Cedar St
New Rochelle, NY 10801
(800) 285-2525
(914) 632-1357 (fax)
Circle #103
See our ad on page 74.

Homecare Products, Inc.
15824 SE 296th St
Kent, WA 98042
(800) 451-1903
(206) 630-8196 (fax)
Circle #101
See our ad on page 134.

River Tank Systems
PO Box 445
Exeter, RI 02822
(800) 808-8822
(401) 294-9510 (fax)
Circle #5
See our ad on page 55.

Home Health Care Services

Kennedy Krieger Institute
707 N Broadway
Baltimore, MD 21205
(800) 873-3377/(410) 550-9400
(410) 550-8217 (fax)
Circle #70
See our ad on page 98.

Olsten Kimberly QualityCare
175 Broadhollow Rd
Melville, NY 11747
(800) 66-NURSE
(508) 383-7514 (fax)
Circle #165
See our ad on page 4.

Vail Products, Inc. (Bed Systems)
235 First St
Toledo, OH 43605
(800) 235-8245
(419) 698-1174 (fax)
Circle #35
See our ad on page 40.

Incontinence Products

All the Best—(Reusables Only)
6846 19th Ave NE
Seattle, WA 98115
(206) 523-1725

ARC Home Health Care Products
RR #4 Box 161
Oneonta, NY 13820
(800) 278-8595
(607) 433-6745 (fax)
Circle #75
See our ad on page 112.

Direct Delivery—Promise Products
PO Box 79603
Houston, TX 77279-9603
(800) 659-8037
(713) 869-5586 (fax)

Express Medical Supply
PO Box 1164
Fenton, MO 63026
(800) 633-2139/(314) 349-8448
(314) 349-8469 (fax)
Circle #157
See our ad on page 74.

G. Hirsch & Co. Inc.
1815 Rollins Rd
Burlingame, CA 94010
(415) 692-8770
(415) 692-1874 (fax)

H.D.I.S. Company, Inc.
1215 Dielman Industrial Ct
St. Louis, MO 63132
(800) 538-1036
(314) 997-0047 (fax)
Circle #14
See our insert on pages 67-70.

Humanicare International, Inc.
1471 Jersey Ave
North Brunswick, NJ 08902
(800) 631-5270
(908) 214-0666 (fax)
Circle #90
See our ad on page 46.

Kimberly-Clark Corporation
PO Box 2020
Neenah, WI 54957-2020
(800) 544-1847
See our ad on page 14.

Mentor Urology
5425 Hollister Ave
Santa Barbara, CA 93111
(800) 328-3863
(805) 967-7108 (fax)

Principle Business Enterprises
Pine Lake Industrial Pk
Dunbridge, OH 43414
(419) 352-1551
(419) 352-8340 (fax)
Circle #89
See our ad on page 89.

Special Products
212 N Market, Ste 315
Wichita, KS 67202-2016
(800) 553-3492
Circle #167
See our ad on page 96.

TAGA
PO Box 313
Somerset, NJ 08873

TMI (Technomarketing, Inc.)
307 Bacon Rd
Rougemont, NC 27572
(919) 477-1387
(919) 477-2294 (fax)
Circle #19
See our ad on page 43.

Woodbury Products
4410 Austin Blvd, Dept 250
Island Park, NY 11558
(800) 777-1111
(516) 431-6793 (fax)
Circle #72
See our ad on page 80.

Medical Equipment Dealers

MED Certified Repair Centers
3223 S Loop 289, Ste 600
Lubbock, TX 79423
(800) 477-6272
Call for location near you.
Circle #93
See our ad on inside back cover.

Passy-Muir, Inc.
4521 Campus Dr, Suite 273
Irvine, CA 92715
(714) 833-8255
(714) 833-8299 (fax)

Vail Products, Inc. (Bed Systems)
235 First St
Toledo, OH 43605
(800) 235-8245
(419) 698-1174 (fax)
Circle #34
See our ad on page 40.

Personal Care/Dental

NR Labs, Inc.
900 E Franklin St
Centerville, OH 45459-5620
(513) 433-9570
Circle #139
See our ad on page 40.

Oralgiene USA, Inc.
421 N Rodeo Dr, Ste 15114
Beverly Hills, CA 90210
(800) 933-ORAL (6725)
Circle #184
See our ad on page 13.

Publishers/Catalogs

Alexander Graham Bell Assoc f/t Deaf
3417 Volta Pl, NW
Washington, DC 20007
(202) 337-5220
(202) 337-8314 (fax)

Attainment Company, Inc.
PO Box 930160
Verona, WI 53593-0160
(800) 327-4269
(800) 942-3865 (fax)

Charles C. Thomas Publishing Co.
2600 South St
Springfield, IL 62794
(217) 789-8980
(217) 789-9130 (fax)
Circle #25
See our ad on page 66.

Communication Skill Builders
3830 E Bellevue
Tucson, AZ 85716
(800) 866-4446
(602) 325-0306 (fax)

Don Johnston, Inc.
1000 N Rand Rd, Bldg 115
Wauconda, IL 60048
(800) 999-4660/(708) 526-2682
(708) 526-4177 (fax)
Circle #144
See our ad on page 112.

Edmark Corp.
PO Box 97021
Redmond, WA 98073-9721
(800) 362-2890
(206) 556-8430 (fax)
Circle #109
See our ad on page 10.

Express Medical Supply
PO Box 1164
Fenton, MO 63026
(800) 633-2139/(314) 349-8448
(314) 349-8469 (fax)
Circle #158
See our ad on page 74.

Interax Training, Inc.
PO Box 473106
Garland, TX 75047-3106
(800) 242-5583

Jason & Nordic Publishers
PO Box 441
Hollidaysburg, PA 16648
(814) 696-2920
(814) 696-4250 (fax)

NCM Consumer Products Division
PO Box 6070
San Jose, CA 95150
(800) 235-7054
(408) 277-6824 (fax)
Circle #68
See our ad on page 104.

The Prader-Willi Forum
40 Holly Ln
Roslyn Heights, NY 11577
(800) 358-0682
(516) 484-7154 (fax)
Circle #43
See our ad on page 71.

Special Needs Project
3463 State St
Santa Barbara, CA 93105
(800) 333-6867

Sportime Abilitations
One Sportime Wy
Atlanta, GA 30340
(800) 850-8602
(800) 845-1535 (fax)
Circle #22
See our ad on page 10.

Tumble Forms
744 W Michigan Ave
Jackson, MI 49203
(517) 789-3377
(517) 789-3333 (fax)
Circle #29
See our ad on back cover.

Voicing!
3857 Birch, Ste 194
Newport Beach, CA 92660
(714) 833-2710
(714) 833-1005 (fax)

Woodbine House
6510 Bells Mill Rd
Bethesda, MD 20817
(800) 843-7323

Ramps/Lifts

Adaptive Driving Systems
21050 Superior St
Chatsworth, CA 91311
(818) 998-1026
(818) 882-0812 (fax)

Aquatic Access, Inc.
411 Dorsey Wy
Louisville, KY 40223
(502) 425-5817
(502) 425-9607 (fax)

Barrier Free Lifts, Inc.
PO Box 4163
Manassas, VA 22110
(703) 361-6531
(703) 361-7861 (fax)
Circle #39
See our ad on page 44.

The Braun Corporation
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT
(219) 946-4670 (fax)
Circle #112
See our ads on pages 9 &11.

Bruno Independent Living Aids
1780 Executive Dr/PO Box 84
Oconomowoc, WI 53066
(800) 882-8133
(414) 567-4341 (fax)
Circle #7
See our ad on page 76.

Crow River Industries
14800 28th Ave N
Minneapolis, MN 55447
(800) 488-7688
(612) 557-8310 (fax)
Circle #119
See our ad on page 92.

GM Mobility Assistance Center
PO Box 9011
Detroit, MI 48202
(800) 323-9935
(800) 833-9935 (TTY)
(313) 974-4383 (fax)
Circle #95
See our ad on page 73.

Homecare Products, Inc.
15824 SE 296th St
Kent, WA 98042
(800) 451-1903
(206) 630-8196 (fax)
Circle #101
See our ad on page 134.

Monmouth Vans, Access & Mobility
5105 Rte 33/34
Farmingdale, NJ 07727
(800) 221-0034
(908) 919-0256 (fax)

Ricon Corporation
12450 Montague St
Pacoima, CA 91331
(818) 899-7588
(818) 890-3354 (fax)
Circle #85
See our ad on page 53.

Rehabilitation Centers/Hospitals

Children's Seashore House
3405 Civic Center Blvd
Philadelphia, PA 19104
(800) 678-3733/(215) 895-3600

Children's Specialized Hospital
150 New Providence Rd
Mountainside, NJ 07092-2590
(908) 233-3720
(908) 233-4176 (fax)
Circle #11
See our ad on page 51.

Cumberland Hospital
9407 Cumberland Rd
New Kent, VA 23124
(800) 368-3472
Circle #74
See our ad on page 99.

Kennedy Krieger Institute
707 N Broadway
Baltimore, MD 21205
(800) 873-3377/(410) 550-9400
(410) 550-8217 (fax)
Circle #70
See our ad on page 96.

Olsten Kimberly QualityCare
175 Broadhollow Rd
Melville, NY 11747
(800) 66-NURSE
(508) 383-7514 (fax)
Circle #165
See our ad on page 4.

The Children's Hospital at St. Joseph's
703 Main St
Paterson, NJ 07503
(201) 977-2500
(201)-684-5025 (fax)
Circle #17
See our ad on page 117.

Voorhees Pediatric Facility
1304 Laurel Oak Rd
Voorhees, NJ 08043
(609) 346-3300
(609) 435-4223 (fax)
Circle #108
See our ad on page 56.

Repair Services—Medical Equipment Dealers

MED Certified Repair Centers
3223 S Loop 289, Ste 600
Lubbock, TX 79423
(800) 477-6272
Call for location near you.
Circle #93
See our ad on inside back cover.

Schools/Camps/Residences

Annandale at Suwanee, Inc.
3500 Annandale Ln/Box 7
Suwanee, GA 30174
(404) 945-8381

Berkshire Meadows
249 N Plain Rd
Housatonic, MA 01236
(413) 528-2523
Circle #10
See our ad on page 107.

Camp Huntington
PO Box 3789
Poughkeepsie, NY 12603
(914) 687-7840

Camphill Special School
1784 Fairview Rd
Glenmoore, PA 19343
(610) 469-9236
(610) 469-9758 (fax)

Children's Care Hospital & School
2501 W 26th St
Sioux Falls, SD 57105
(800) 584-9294/(605) 336-1840

CIB/Oak Hill
120 Holcomb St
Hartford, CT 06112
(203) 242-2274
(203) 242-3103 (fax)

Crotched Mountain
1 Verney Dr
Greenfield, NH 03047
(603) 547-3311
Circle #73
See our ad on page 75.

Crystal Springs School
38 Narrows Rd, Box 372
Assonet, MA 02702
(508) 644-5537
(508) 644-3101, ext 372 (fax)
Circle #124
See our ad on page 72.

Dr. Gertrude A. Barber Center
136 East Ave
Erie, PA 16507
(814) 453-7661
(814) 454-2771 (fax)

Elwyn, Inc.
111 Elwyn Rd
Elwyn, PA 19063-4699
(800) 345-8111/(610) 891-2000
Circle #79
See our ad on page 82.

Evergreen Center
345 Fortune Blvd
Milford, MA 01757
(508) 478-5597
(508) 634-3251 (fax)
Circle #106
See our ad on page 90.

Heartspring
2400 Jardine Dr
Wichita, KS 67219
(800) 835-1043
(316) 262-0170 (fax)
Circle #3
See our ad on page 54.

HMS School for Children with CP
4400 Baltimore Ave
Philadelphia, PA 19104
(215) 222-2566
Circle #77
See our ad on page 51.

Keystone City Residence & Camp
c/o 406 N Wash. Ave
Scranton, PA 18503
(800) 232-1753
(717) 342-3461 (fax)
Circle #48
See our ad on page 71.

LARC School, Inc.
Creek Rd & Park Dr
Bellmawr, NJ 08031
(609) 933-3725
(609) 933-3158 (fax)

League School of Boston
225 Nevada St
Newtonville, MA 02160
(617) 964-3260
Circle #24
See our ad on page 88.

Martha Lloyd Community Services
190 W Main St
Troy, PA 16947
(717) 297-2185
Circle #78
See our ad on page 105.

Meeting Street Center
667 Waterman Ave
East Providence, RI 02914
(401) 438-9500
(401) 438-3690 (TDD)
(401) 438-3760 (fax)
Circle #83
See our ad on page 44.

Melmark
Wayland Rd
Berwyn, PA 19312
(610) 353-1726
(610) 353-8528 (fax)
Circle #69
See our ad on page 113.

Natl Christian Resource Ctr on MR
700 Hoffman Dr
Watertown, WI 53094
(800) 369-INFO
Circle #84
See our ad on page 132.

New England Villages
664 EP School St
Pembroke, MA 02359
(617) 293-5461
Circle #21
See our ad on page 39.

St. Coletta's of Mass.
400 Washington St
Hanover, MA 02339
(617) 826-6371
(617) 826-6474 (fax)
Circle #162
See our ad on page 104.

Stewart Home School
Box 20
Frankfort, KY 40601
(502) 875-4664
Circle #4
See our ad on page 56.

The Devereux Foundation
19 S Waterloo Rd, PO Box 400
Devon, PA 19333
(800) 345-1292, ext 3045
(610) 971-4600 (fax)
Circle #107
See our ad on page 91.

The Guided Tour's Camp Lee Mar
7900 Old York Rd, Ste 114-B
Elkins Park, PA 19027-2339
(215) 782-1370
(215) 635-2637 (fax)
Circle #136
See our ad on page 116.

The Learning Center
411 Waverly Oaks Rd
Waltham, MA 02154
(617) 893-6000

The New England Center for Autism
33 Turnpike Rd
Southboro, MA 01772
(508) 481-1015
Circle #76
See our ad on page 46.

Willow River Farms
PO Box 450
San Felipe, TX 77473
(409) 885-4121
Circle #91
See our ad on page 80.

Scooters

Bruno Independent Living Aids
1780 Executive Dr/PO Box 84
Oconomowoc, WI 53066
(800) 882-8133
(414) 567-4341 (fax)
Circle #8
See our ad on page 76.

Ortho-Kinetics, Inc.
W220 N 507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (fax)

Seating & Positioning

Adaptive Design Labs
15 Standish Ave
West Orange, NJ 07052
(201) 736-4443
(201) 736-3673 (fax)
Circle #2
See our ad on page 98.

Bruno Independent Living Aids
1780 Executive Dr/PO Box 84
Oconomowoc, WI 53066
(800) 882-8133
(414) 567-4341 (fax)
Circle #9
See our ad on page 76.

Child Quest, Inc. Seatkeeper
PO Box 18595
Austin, TX 78760
(800) 732-8533
(512) 385-6178 (fax)
Circle #38
See our ad on page 96.

Columbia Medical Mfg. Corp.
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612
(310) 305-1718 (fax)
Circle #153
See our ads on pages 12 & 121.

Consumer Care Products, Inc.
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353
(414) 459-9070 (fax)
Circle #138
See our ad on page 90.

Convaid Products, Inc.
PO Box 2458
Palos Verdes, CA 90275
(800) 552-1020/(310) 539-6814
(310) 539-3670 (fax)
Circle #127
See our ad on page 81.

Express Medical Supply
PO Box 1164
Fenton, MO 63026
(800) 633-2139/(314) 349-8448
(314) 349-8469 (fax)
Circle #159
See our ad on page 74.

Freedom Designs, Inc.
2241 Madera Rd
Simi Valley, CA 93065
(800) 331-8551/(805) 582-0077
(805) 582-1509 (fax)
Circle #169
See our ad on page 124.

James Leckey Design, Inc.
360 Merrimack St
Riverwalk Bldg 5
Lawrence, MA 01843
(508) 691-5220
(508) 691-5230 (fax)
Circle #57
See our ad on page 39.

Jay Medical Ltd.
PO Box 18656
Boulder, CO 80202
(800) 648-8282/(303) 442-5529
(303) 442-3855 (fax)
Circle #148
See our ad on page 108.

Jesana Ltd.
PO Box 17
Irvington, NY 10533
(800) 443-4728
(914) 591-4320 (fax)
Circle #180
See our ad on page 97.

Kennedy Krieger Institute
707 N Broadway
Baltimore, MD 21205
(800) 873-3377/(410) 550-9400
(410) 550-8217 (fax)
Circle #71
See our ad on page 98.

Meeting Street Center
667 Waterman Ave
East Providence, RI 02914
(401) 438-9500
(401) 438-3690 (TDD)
(401) 438-3760 (fax)
Circle #83
See our ad on page 44.

Mulholland Positioning Systems
PO Box 391, 215 N 12th St
Santa Paula, CA 93061
(800) 543-4769
(805) 933-1082 (fax)
Circle #64

Ortho-Kinetics, Inc.
W220 N 507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (fax)

Rifton
PO Box 901
Rifton, NY 12471-0901
(800) 374-3866
(914) 658-8065 (fax)
Circle #41
See our ad on page 52.

Snug Seat
1081 Independence Point Pkwy
Matthews, NC 28106
(704) 847-0772
(704) 847-9577 (fax)
Circle #52
See our ad on page 57.

Special Designs, Inc.
PO Box 130
Gillette, NJ 07933
(908) 464-8825
(908) 464-8251 (fax)
Circle #130
See our ad on page 98.

Taylor Made Healthcare
10 W 9th Ave
Gloversville, NY 12078
(800) 258-0942
(518) 773-9375 (fax)
Circle #134
See our ad on page 72.

Tumble Forms
744 W Michigan Ave
Jackson, MI 49203
(517) 789-3377
(517) 789-3333 (fax)
Circle #28
See our ad on back cover.

Software

Articulate Sys. Voice Recognition
600 W Cummings Pk, Ste 4500
Woburn, MA 01801
(800) 443-7077
(617) 935-0490 (fax)

Edmark Corp.
PO Box 97021
Redmond, WA 98073-9721
(800) 362-2890
(206) 556-8430 (fax)
Circle #109
See our ad on page 10.

KidTECH/SoftTouch
3204 Perry Pl
Bakersfield, CA 93306
(805) 873-8744
(805) 871-9679 (fax)
Circle #177
See our ad on page 42.

Laureate Learning Systems, Inc.
110 E Spring St
Winooski, VT 05404
(800) 562-6801/(802) 655-4755
(802) 655-4757 (fax)
Circle #45
See our ad on page 52.

Marblesoft
12301 Central Ave NE, Ste 205
Blaine, MN 55434
(612) 755-1402
(612) 755-1402 (fax, call first)
Circle #16
See our ad on page 42.

RJ Cooper & Associates
24843 Del Prado, #283
Dana Point, CA 92629
(800) RJCOOPER
(714) 240-9785 (fax)
Circle #82
See our ad on page 79.

Sports/Recreation/Family

Aquatic Therapy
1903 E B Ave
Plainwell, MI 49080
(616) 349-9049
(616) 349-9049 (fax)
Circle #118
See our ad on page 42.

Bali Dynamics Int'l, Inc.
1616 Glenarm Pl., Ste #1900
Denver, CO 80202
(800) 752-2255
(303) 893-0524 (fax)
Circle #111
See our ad on page 113.

Flaghouse, Inc.
150 N MacQuesten Pkwy
Mt. Vernon, NY 10550
(800) 793-7900/(914) 699-1900
(800) 793-7922 (fax)
Circle #132
See our ad on page 88.

Jay Medical Ltd.
PO Box 18656
Boulder, CO 80202
(800) 648-8282/(303) 442-5529
(303) 442-3855 (fax)
Circle #149
See our ad on page 108.

Jesana Ltd.
PO Box 17
Irvington, NY 10533
(800) 443-4728
(914) 591-4320 (fax)
Circle #181
See our ad on page 97.

River Tank Systems
PO Box 445
Exeter, RI 02822
(800) 808-8822
(401) 294-9510 (fax)
Circle #5
See our ad on page 55.

Rock N'Roll Cycles
PO Box 1558
Levelland, TX 79336
(800) 654-9664
(806) 894-9646 (fax)
Circle #173
See our ad on page 41.

Roleez Wheel System
5711A Sellger Dr/Dept E
Norfolk, VA 23502
(800) 369-1390/(804) 461-1122
(804) 461-0383 (fax)
Circle #47
See our ad on page 112.

Top End by Action
4501 63rd Cir N
Pinellas Park, FL 34665
(800) 532-8677/(813) 522-8677
(813) 522-1007 (fax)

Standing Equipment

James Leckey Design, Inc.
360 Merrimack St
Riverwalk Bldg 5
Lawrence, MA 01843
(508) 691-5220
(508) 691-5230 (fax)
Circle #58
See our ad on page 39.

Mulholland Positioning Systems
PO Box 391, 215 N 12th St
Santa Paula, CA 93061
(800) 543-4769
(805) 933-1082 (fax)
Circle #65

Ortho-Kinetics, Inc.
W220 N 507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (fax)

Snug Seat
1081 Independence Point Pkwy
Matthews, NC 28106
(704) 847-0772
(704) 847-9577 (fax)
Circle #55
See our ad on page 57.

Strollers

Columbia Medical Mfg. Corp.
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612
(310) 305-1718 (fax)
Circle #154
See our ads on pages 12 & 121.

Convaid Products, Inc.
PO Box 2458
Palos Verdes, CA 90275
(800) 552-1020/(310) 539-6814
(310) 539-3670 (fax)
Circle #128
See our ad on page 81.

Jesana Ltd.
PO Box 17
Irvington, NY 10533
(800) 443-4728
(914) 591-4320 (fax)
Circle #182
See our ad on page 97.

Kid-Kart
732 Cruiser Ln
Belgrade, MT 59714
(800) 388-5278
(406) 388-1081 (fax)
Circle #99
See our ad on page 12.

Mulholland Positioning Systems
PO Box 391, 215 N 12th St
Santa Paula, CA 93061
(800) 543-4769
(805) 933-1082 (fax)
Circle #66

Racing Strollers, Inc/ Baby Jogger
PO Box 2189
Yakima, WA 98907-2189
(800) 241-1848
(509) 453-7732 (fax)
Circle #63
See our ad on page 96.

Snug Seat
1081 Independence Point Pkwy
Matthews, NC 28106
(704) 847-0772
(704) 847-9577 (fax)
Circle #54
See our ad on page 57.

Stroller-Pack
PO Box 20707
Juneau, AK 99802
(800) 487-9652/(907) 463-4843
(907) 463-4889 (fax)
Circle #164
See our ad on page 90.

Tumble Forms
744 W Michigan Ave
Jackson, MI 49203
(517) 789-3377
(517) 789-3333 (fax)
Circle #30
See our ad on back cover.

Telephone Equipment

InvoTek Corporation
700 W 20th St, ENRC
Fayetteville, AR 72701
(800) 576-6661
(501) 575-7446

Ultratec, Inc.
450 Science Dr
Madison, WI 53711
(800) 482-2424 (V/TTY)
(608) 238-3008 (fax)

Travel/Leisure/Hotels

The Guided Tour—Adult Travel
7900 Old York Rd, Ste 114-B
Elkins Park, PA 19027-2339
(215) 782-1370
(215) 635-2637 (fax)

Vans

The Braun Corporation
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT
(219) 946-4670 (fax)
Circle #114
See our ads on pages 9 & 11.

Chrysler Automobility Program
PO Box 3124
Bloomfield Hills, MI 48302-3124
(800) 225-9877
Circle #146
See our ad on page 47.

Ford Mobility Motoring Program
PO Box 529
Bloomfield Hills, MI 48303-9857
(800) 952-2248
(810) 621-3082 (fax)
Circle #135
See our ad on inside front cover.

GM Mobility Assistance Center
PO Box 9011
Detroit, MI 48202
(800) 323-9935
(800) 833-9935 (TTY)
(313) 974-4383 (fax)
Circle #96
See our ad on page 73.

Ricon Corporation
12450 Montague St
Pacoima, CA 91331
(818) 899-7588
(818) 890-3354 (fax)
Circle #87
See our ad on page 53.

Vantage Mini Vans
5214 S 30th St
Phoenix, AZ 85040
(800) 348-8267
(602) 243-9843 (fax)
Circle #102
See our ad on page 58.

Van Conversions

Adaptive Driving Systems
3534 Empleo St, Ste B
San Luis Obispo, CA 93401
(805) 549-7996
(818) 882-0812 (fax)

Arcola Mobility
51 Karo Rd
Carlstadt, NJ 07072
(800) ARCOLA-1/(201) 507-8500

The Braun Corporation
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT
(219) 946-4670 (fax)
Circle #115
See our ads on pages 9 & 11.

Drive-Master, Inc.
9 Spielman Rd
Fairfield, NJ 07004
(201) 808-9709

Forward Motions
214 Valley St
Dayton, OH 45404
(513) 222-5001

GM Mobility Assistance Center
PO Box 9011
Detroit, MI 48202
(800) 323-9935
(800) 833-9935 (TTY)
(313) 974-4383 (fax)
Circle #97
See our ad on page 73.

Handicap Vehicle Specialists, Inc.
3306 E Washington, #106
Phoenix, AZ 85034-1624
(602) 275-3325
(602) 275-1536 (fax)

Independent Mobility Systems
4100 W Piedras
Farmington, NM 87401
(800) IMS VANS
(505) 326-4846 (fax)

Lift Aids, Inc.
2381 Pecan Ct
Fort Worth, TX 76117
(817) 429-7141 (metro)
(817) 834-3881
(817) 831-7842 (fax)

Monmouth Vans, Access & Mobility
5105 Rte 33/34
Farmingdale, NJ 07727
(800) 221-0034

New Era Transportation
810 Moe Dr
Akron, OH 44310
(800) 638-8267/(216) 633-1118
(216) 633-0330 (fax)

Ricon Corporation
12450 Montague St
Pacoima, CA 91331
(818) 899-7588
(818) 890-3354 (fax)
Circle #88
See our ad on page 53.

Vantage Mini Vans
5214 S 30th St
Phoenix, AZ 85040
(800) 348-8267
(602) 243-9843 (fax)
Circle #102
See our ad on page 58.

Van Rentals

Wheelers, Accessible Van Rentals
6614 W Sweetwater
Glendale, AZ 85304
(800) 456-1371
(602) 878-0501 (fax)

Wheelchair Getaways, Inc.
PO Box 605
Versailles, KY 40383
(800) 642-2042
(606) 873-8039 (fax)

Walking Aids

Jesana Ltd.
PO Box 17
Irvington, NY 10533
(800) 443-4728
(914) 591-4320 (fax)
Circle #183
See our ad on page 97.

Wheelchairs, Manual

Convaid Products, Inc.
PO Box 2458
Palos Verdes, CA 90275
(800) 552-1020/(310) 539-6814
(310) 539-3670 (fax)
Circle #129
See our ad on page 81.

Freedom Designs, Inc.
2241 Madera Rd
Simi Valley, CA 93065
(800) 331-8551/(805) 582-0077
(805) 582-1509 (fax)
Circle #170
See our ad on page 124.

Kid-Kart
732 Cruiser Ln
Belgrade, MT 59714
(800) 388-5278
(406) 388-1081 (fax)
Circle #100
See our ad on page 12.

MED Certified Repair Centers
3223 S Loop 289, Ste 600
Lubbock, TX 79423
(800) 477-6272
Call for location near you.
Circle #93
See our ad on inside back cover.

Mulholland Positioning Systems
PO Box 391, 215 N 12th St
Santa Paula, CA 93061
(800) 543-4769
(805) 933-1082 (fax)
Circle #67

Ortho-Kinetics, Inc.
W220 N 507 Springdale Rd
Waukesha, WI 53187
(800) 558-7786
(414) 542-0625 (fax)

Rock N'Roll Cycles
PO Box 1558
Levelland, TX 79336
(800) 654-9664
(806) 894-9646 (fax)
Circle #174
See our ad on page 41.

Snug Seat
1081 Independence Point Pkwy
Matthews, NC 28106
(704) 847-0772
(704) 847-9577 (fax)
Circle #53
See our ad on page 57.

TMI (Technomarketing, Inc.)
307 Bacon Rd
Rougemont, NC 27572
(919) 477-1387
(919) 477-2294 (fax)
Circle #20
See our ad on page 39.

Top End by Action
4501 63rd Cir N
Pinellas Park, FL 34665
(800) 532-8677/(813) 522-8677
(813) 522-1007 (fax)

Wheelchairs, Powered

The Braun Corporation
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT
(219) 946-4670 (fax)
Circle #116
See our ads on pages 9 & 11.

Innovative Products, Inc.
830 S 48th St
Grand Forks, ND 58201
(800) 950-5185/(701) 772-5185
(701) 772-5284 (fax)
Circle #110
See our ad on page 96.

MED Certified Repair Centers
3223 S Loop 289, Ste 600
Lubbock, TX 79423
(800) 477-6272
Call for location near you.
Circle #93
See our ad on inside back cover.

Other

Assoc of Birth Defect Children
827 Irma Ave
Orlando, FL 32803
(800) 313-ABDC
Circle #62
See our ad on page 71.

Bustop Alert
254 Charlevoix
Grosse Pointe Farms, MI 48236
(313) 885-8961
(313) 885-7075 (fax)
Circle #60
See our ad on page 82.

Diestco Manufacturing
PO Box 6504
Chico, CA 95927
(800) 795-2392
(916) 893-2635 (fax)
Circle #105
See our ad on page 71.

Melmark
Wayland Rd
Berwyn, PA 19312
(610) 353-1726
(610) 353-8528 (fax)
Circle #69
See our ad on page 113.

Mentor Urology
5425 Hollister Ave
Santa Barbara, CA 93111
(800) 328-3863
(805) 967-7108 (fax)

Pro Battery Specialists
890 W 23rd St
Hialeah, FL 33010
(800) 572-4888
(305) 884-3483 (fax)
Circle #49
See our ad on page 80.

Rhamdec, Inc./Mydesc Division
476 Ellis St
Mountain View, CA 94043-2240
(415) 965-3251
(415) 965-2240 (fax)
Circle #37
See our ad on page 97.

Sportime Abilitations
One Sportime Wy
Atlanta, GA 30340
(800) 850-8602
(800) 845-1535 (fax)
Circle #23
See our ad on page 10.

Did I Hear You Say Help?

National Christian Resource Center on Mental Retardation
a service of:
Bethesda
LUTHERAN HOMES AND SERVICES, INC.
700 Hoffman Dr.
Watertown, WI 53094
A.L. Napolitano
Executive Director
Call 1-800-369-INFO

- ☐ Are you looking for appropriate services for yourself, your family member or client?
- ☐ Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

Then call our toll-free hotline 1-800-369-INFO.

We offer:

- Lists of services in specified geographic areas.
- Referrals to advocacy and support groups.
- Referrals to religious education programs.
- Lists of religious materials.

Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

Circle # 84

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Sold separately for $9.95
Call 800-535-1910

Put Your Honey in a Gunny

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GUNNY SACK™
Lap, Leg and Feet Cover
- Fleece lined for warmth
- 100% waterproof

To Order Call
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DIESTCO Manufacturing
P.O. Box 6504 • Chico, CA 95927

Remember to tell them you saw it in EXCEPTIONAL PARENT!

Market Place

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Ross' Bibs—Haco, Inc.
PO Box 5642, Asheville, NC 28813
Call (704) 274-0075
Bibs are made of machine washable, heavy duty vinyl. Large child size is $13.95; small adult size is $15.95; plus $2.00 shipping. Call for more information.

Clothing

Richman Cotton Company
100% Cotton Clothing & Blankets
Easy to dress. Easy to see.
FREE Catalog. 800-992-8924.

Consulting

Paynter Educational Partners
P.O. Box 42829-1001
Houston, TX 77242-2829
(713) 568-7954
Call for FREE Guide for parents & FREE 20 minute consultation for education/social skill problems or write for FREE copy of Guide.

Cribs & Youth Beds

HARD Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
The #1 mfg. sets the standard for safety in hospitals. 216 colorful models available. HARD will adapt products to meet your special requirement.

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National

American Discount Medical
Pediatric Equipment Specialists. Hundreds of major brands of equipment & supplies discounted to 50%—Tumbleforms, Jay, Roho, Kaye, Snug Seat, Columbia, Convaid, Guardian, E&J, Invacare & others. Call for FREE BROCHURE. 1-800-877-9100.

Health Science, Inc.
418 Wall Street, Princeton, NJ 08540
(609) 924-7616 & (800) 841-8923
Authorized Dealer for:
Ablenet • Abovo • Ability Research • Canon • Franklin • Innocomp • IntelliTools • Mayer-Johnson • MultiVoice by IAT • Tash • Tiger • Toys for Special Children
Take advantage of our loaner, leasing and discount program.

Massachusetts

Atlantic Rehab., Inc.
81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
Atlantic Rehab. specializes in Pediatric Mobility and Seating. Sales and Service. Please call for more information.

Incontinence

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
ATTENDS YOUTH BRIEFS fits children 35–75 lbs. $51.95/cs (96), Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

H.D.I.S.
1215 Dielman Industrial Court
Olivette, MO 63132
(800) 538-1036
See our ad in this issue.

Summers Laboratories, Inc.
Collegeville, PA 19426
(800) 533-SKIN (7546)
Triple Paste™ for diaper rash and chronic irritation. Used at leading children's hospitals. Available without prescription. Call now for free treatment information.

Monitoring Systems

Care Electronics
5741 Arapahoe Rd., Suite 2A
Boulder, CO 80303
(303) 444-CARE (2273)
WanderCARE Systems notify caregivers when their wanderer leaves home. Locate them up to ONE MILE away. FREE catalog!

Software

UCLA Microcomputer Project
1000 Veteran Avenue/Rm 23-10
Los Angeles, CA 90024
(310) 825-4821
Catalog of dev. appropriate software for children w/disab. 18 mths-5 yrs. Apple, Mac, IBM, cause/effect, game format, basic preschool concepts

BOOKS, AUDIO/VIDEO & EDUCATIONAL MATERIAL

Books for Parents and Professionals

Turtle Books
Approved by the American Academy of Pediatrics. These upbeat stories with warm, colorful illustrations address real issues found in the lives of real children with disabilities. Provide a bridge of understanding for your children with disabilities, siblings & friends. **FREE** Brochure. **Jason and Nordic Publishers,** PO Box 441, Hollidaysburg, PA 16648. FAX (814) 696-4250

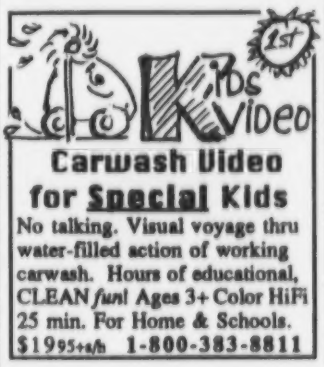
Catalogs

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. **Special Needs Project,** 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Educational Materials

Free—The 1995 Woodbine House/Special-Needs Collection, a catalog of excellent books for parents, children, and professionals on autism, CP, Down syndrome, Tourette syndrome, mental retardation, visual impairment, physical disabilities, special education, and more. **Woodbine House,** 6510 Bells Mill Road, Bethesda, MD 20817, (800) 843-7323.

Videotapes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No talking. Visual voyage thru water-filled action of working carwash. Hours of educational, CLEAN fun! Ages 3+ Color HiFi 25 min. For Home & Schools.
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Interax Video
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Illustrates 1200+ signs based on ASL. Six videos with 6.5 hrs. Graphics provide reference of equivalent English word. Free Brochure. $199 (+$4.50 s&h). **Interax Training, Inc.,** PO Box 473106, Garland, TX 75047-3106, (800) 242-5583.

Publications

Parent Pro Publications
Educational "know-how" for parents. Effective, easy to use materials. HOMEWORK Troubleshooter $14.00 Power CLASSROOM OBSERVATION $12.00. Free catalog.
5374 Linda Vista Road, Suite D
San Diego, CA 92110
(619) 688-1323

VAN CONVERSION DEALERS

Connecticut

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center: raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Illinois

C & C Ford–Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMDEA member.

Indiana

Forward Motions
214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

C & C Ford–Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMDEA member.

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C & C Ford–Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMDEA member.

Forward Motions
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Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

(Listings continued on next page)

VAN CONVERSION DEALERS

Massachusetts

Handicap Mobility, Inc.
81 Pond Street
Norfolk, MA 02056
(508) 384-1220
Handicap Mobility, Inc. is the premier installer and service center for vehicles with adaptive equipment in Southern New England.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

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Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

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Ohio

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214 Valley Street
Dayton, OH 45404
(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

C & C Ford–Mercury
5th & Monroe Streets
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors, Braun lifts & tie-downs installed by certified technicians. NMEDA member.

Pennsylvania

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9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

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Rollup/1' Curb Ramp, 5' Step Ramp and 8' All Purpose Ramp

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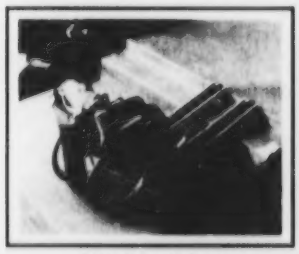
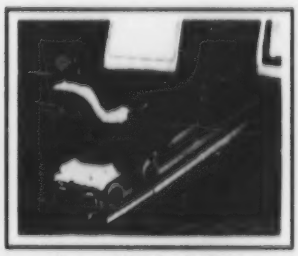
- Catch Buttons
- One Year Warranty

Look for this Seal of Quality

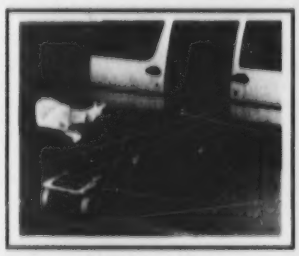


R1000 5' Portable Ramp

Overcome life's obstacles with EZ-ACCESS™ Portable Ramps for Wheelchairs and Scooters.



Vanramp R2000 7' or R6000 10'



R3000 8' Scooter Ramp

Years of Quality Manufacturing by the Physically Challenged

HOMECARE PRODUCTS, INC.
Kent, WA 98042
206-631-4633 1-800-451-1903
FAX 206-630-8196

Circle # 101

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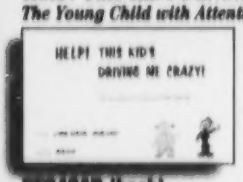
HELP! THIS KID'S DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder



L. ADKINS & J. CADY
Information about typical behavior characteristics; suggestions on how to foster the development of appropriate behavior.

PE040AD (book) **$5.00**
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ACTIVITIES FOR DEVELOPING PRE-SKILL CONCEPTS IN CHILDREN WITH AUTISM
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Each activity is designed to tell educators what they are doing, why they are doing it and what materials they will need to teach the activity. The activities are adaptable for children of all levels.
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A Journey into Language
RUSSELL MARTIN
A heartfelt account of an autistic child struggling to gain the gift of speech, exposing the depth of the mind and heart.
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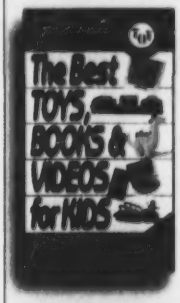
MARTIN KOZLOFF
Focuses on a parent training program that shows how to improve the environment of the autistic child.
BL063OD **$14.95**

DISABILITY, GENERAL



THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS
JOANNE OPPENHEIM & STEPHANIE OPPENHEIM
A guide to over 1000 kid-tested, classic and new products with features on products for kids with special needs.
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CAN'T YOUR CHILD SEE?
A Guide for Parents of Visually Impaired Children
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Practical guidelines for helping visually impaired children reach their full potential
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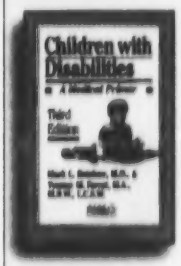
PEARL BUCK
Brings back into print Buck's inspiring account of her struggle to help her daughter with mental retardation.
WB006MR **$14.95**



CHILDREN WITH DISABILITIES: ***A Medical Primer***
M. BATSHAW
For parents and professionals. Over 200 detailed illustrations, an extensive glossary, and section on syndromes.
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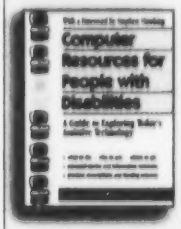

COMPUTER RESOURCES FOR PEOPLE WITH DISABILITES: ***A Guide to Exploring Today's Assistive Technology***
THE ALLIANCE FOR TECHNOLOGY ACCESS
Provides user-friendly support, information, and up-to-date answers.
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Basics of the field—history, classification, and definitions—but also discusses controversies: nature vs. nurture, deinstitutionalization vs. institutionalization, and the educability hypothesis.
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AN INTRODUCTION TO SPINA BIFIDA
D.G. MCLONE, M.D., PH.D
The purpose of this booklet is to aid the parents, family and the non-medical people who care for the child born with spina bifida.
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P.J. ADKINS, ED.D
The information compiled in this booklet is for parents and teachers, to help in the dilemma which has affected all those.
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S.L. SLOAN, PH.D
This book was written to answer the questions that families and persons with spina bifida may have about their sexuality.
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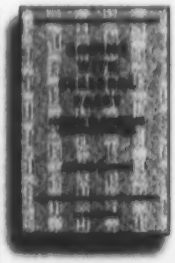

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Provides answers to more than 300 questions that have been carefully researched.
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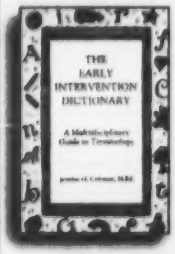

THE EARLY INTERVENTION DICTIONARY
A Multi-disciplinary Guide to Terminology
JEANINE COLEMAN, M.ED.
Defines and clarifies terms used by the many different medical, therapeutic, and educational professionals who provide early intervention services.
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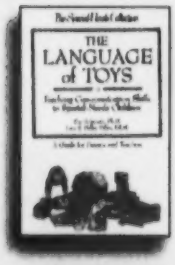
THE ILLUSTRATED DIRECTORY OF DISABILITY PRODUCTS
MONTE MACE
Shows hundreds of products along with names, addresses and phone numbers so consumers can get more information.
TP026OD **$12.95**



THE LANGUAGE OF TOYS
Teaching Communication Skills to Special-Needs Children
S. SCHWARTZ & J. MILLER
Teaches parents how to improve their child's communication skills at home with fun, easy-to-follow exercises.
WB02000 **$14.95**

LITTLE CHILDREN, BIG NEEDS: ***Parents Discuss Raising Children with Exceptional Needs***
DON WEINHOUSE, PH.D. AND MARILYN WEINHOUSE, M.A.
What are the concerns of parents who raise disabled children? Contains candid interviews with 50 families of children with a wide range of disabilities.
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PHYSICIANS' GUIDE TO RARE DISEASES
EDITED BY J.G. THOENE
Over 1,000 pgs. Contains information on approximately 700 disorders.
DP02100 **$75.50**

PLANNING FOR THE FUTURE
Providing a Meaningful Life for a Child with a Disability after Your Death
MARK RUSSELL
AP02400 **$24.95**

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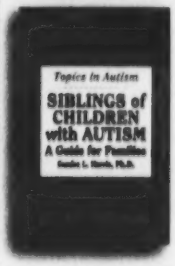
M. HANSON & S. HARRIS
Provides information to parents on how motor development influences other areas of development.
PE049PD **$27.00**

YOU, YOUR CHILD AND "SPECIAL" EDUCATION
A Guide to Making the System Work
BARBARA COYNE CUTLER
Shows parents how to obtain the educational services their child rightfully deserves.
PB05300 **$22.00**

SIBLINGS

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals.
EP001EP **$14.95**



SIBLINGS OF CHILDREN WITH AUTISM
A Guide for Families
S.L. HARRIS, PH.D.
Understand sibling relationships, how autism affects them and what families can do to support their other children.
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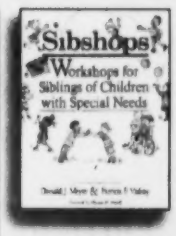

SIBSHOPS
Workshops for Siblings of Children with Special Needs
DONALD J. MEYER
How to provide peer support and educational opportunities for sisters and brothers of children with special needs.
PB08600 **$32.00**

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WHEN YOUNG CHILDREN ARE INJURED: ***Families as Caregivers in Hospitals and at Home***
J. HALTIWANGER & M. LASH
A book about the family's role in caregiving when a young child is injured.
EP085ML **$7.50**
(Includes shipping charges)

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
MARILYN LASH
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML **$7.50**
(Includes shipping charges)

WHEN YOUR CHILD IS SERIOUSLY INJURED
The Emotional Impact on Families
MARILYN LASH
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML **$4.50**
(Includes shipping charges)

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JOEY AND SAM
I. KATZ & E. RITVO, M.D.
A heartwarming storybook about autism, a family, and a brother's love.
RL099AM **$9.95**

MY BUDDY
A. OSOFSKY
Buddy is the best dog a boy could have. Fully illustrated, this book demonstrates the desires of the disabled to be independent.
HH098CB **$5.95**

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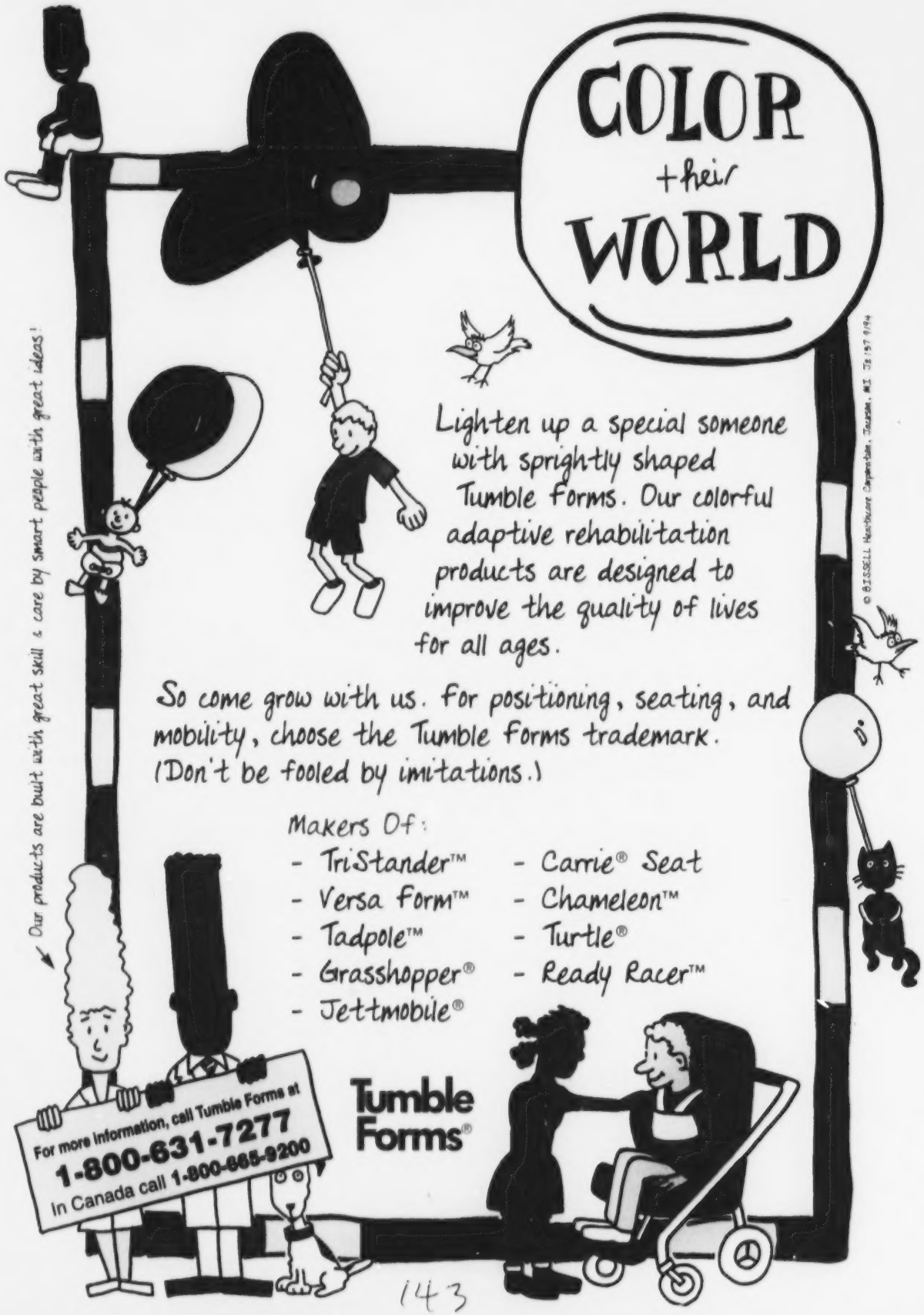
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Circle # 26

FEBRUARY 1995

EXCEPTIONAL PARENT

The Magazine for Families and Professionals

EARLY CHILDHOOD

- ASSESSMENT
- DAYCARE
- TRANSITIONS

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FEBRUARY 1995
VOL. 25, ISSUE 2

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COVER: *Dana Reed and son Kyle, shown on the cover in a 1987 photograph (by Natalie Fobes/The Seattle Times), and above in a 1994 photo (by James May), live in Monroe, Washington with mom Debbie and brothers B.J., 10, and Jason, 6. Kyle, who has Down syndrome, is now eight years old.*

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EDITOR'S DESK

STANLEY D. KLEIN, PH.D.

We have come a long way from the days when parents of infants with special needs were given but two choices—take your baby home and "accept," or "place" your child. Neither choice served the needs of families or offered hope for the future. Today, there are far more positive choices and opportunities. For many infants, young children and their families, participation in early intervention and preschool daycare programs are essential beginnings.

As parents and professionals work to provide optimal opportunities for children to thrive, they need to determine the best ways to utilize resources to meet a child's special needs. This is a never-ending, challenging and complicated process requiring respectful, ongoing collaboration between parents and professionals—another challenging and complicated process! But because we, as humans, wish our lives and decisions were less burdensome, we are attracted to quick and easy answers. This is true of our efforts in early childhood programs; we want to know exactly what to do (assessment), get on with doing it (intervention), and move on to next step (transition)! It is as if we believe everyone knows how to help children grow into empowered, productive and joyful adults, or that we believe we need not be concerned because some automated teller will deliver whatever is necessary.

With the help of creative, energetic parents and professionals from Texas to Nova Scotia, this issue illustrates the beauty of inclusive early childhood programs that are carried out with careful assessment, collaboration, training and appropriate interventions. At the same time, articles on assessment and transition, along with positive and negative stories of real children in real programs, demonstrate that while nurturing all children is hard work, nurturing children with special needs is even harder. Accordingly, when our efforts are not as successful as we wish, let us not blame a child's disability, parents' perceived inadequacies or even professionals' lack of training. Instead, caring parents and professionals can learn from one another and from the children and move forward.

Our goal is to help parents become better consumers and to allow them, along with health and education professionals, to benefit from existing know-how and to work to improve current options and to create new and better choices for children and families.

Mixed messages

Although most of this issue is up-beat, the *Guest Editorial* and *Networking* from the NPND are wake-up calls to all. Thoughtful public policy leaders—people with disabilities and parents—warn that the mood in Washington may be dangerous to children and young adults with disabilities and their families. Once again, it is time to educate political leaders so they can appreciate that the opportunities and choices for parents and children described in this issue have an important history and have evolved because dedicated parents and professionals have insisted that public attitudes change and barriers be removed.

Unfortunately, these messages have forced us to postpone our December promise to report on the failed congressional health care reform proposals that reflected the concerns of people with disabilities, family members and professionals.

Remembering Irv Zola

In February 1994, we initiated a new regular department—*Role Models*. In each subsequent issue, adults with disabilities have shared their personal stories, hopes and dreams. In this issue, we mourn Irving Zola's recent death while honoring his distinguished life by sharing a small sample of his powerful writings. Readers throughout the world can learn from his model.

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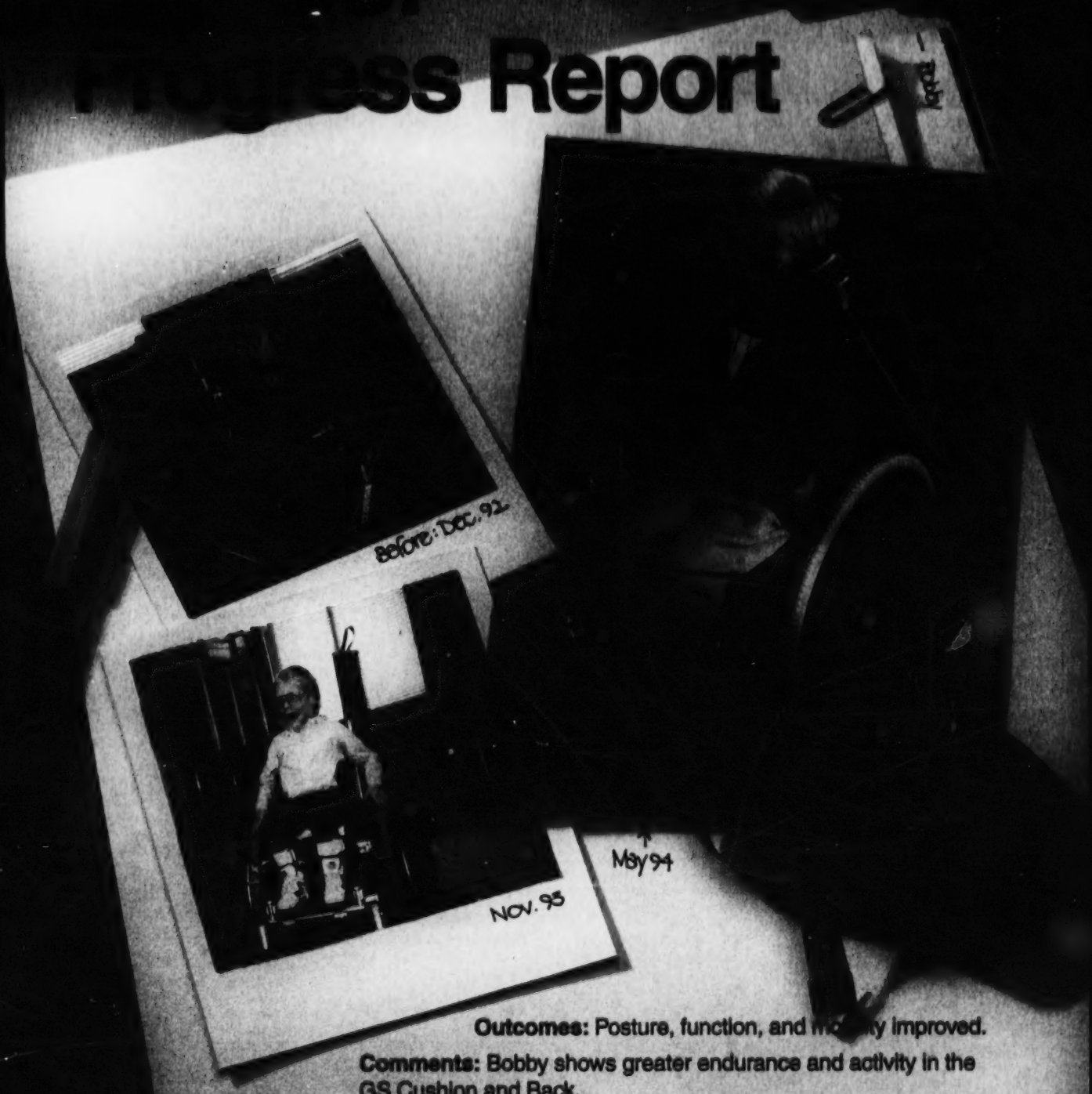
EPI 147

ress Report



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Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

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LETTERS

A Few Miles on the Ol' Rocker

Thanks to Edward Sample for his *Fathers' Voices* piece, "A Few Miles on the Ol' Rocker" (December 1994). I am one of those people who call needing information about children. The other day I made a call and a father answered. I scheduled the appointment for the family interview with him. He was very clear about intending to be a part of the process.

Why do we ask for the mother when we call or visit? Probably because she is the one who usually is there; probably because that's the way we've always done it; probably because if we regularly include dads, we have to work overtime and thus take away from our own families. The probabilities could go on forever, depending on the individual caller and family.

Please know that most of us understand the importance of an "intact" family. We appreciate the moral, physical and financial support that fathers and mothers give to each other and, therefore, are better able to give to their children.

Thank you again for calling our attention to our need to be ever sensitive to each family situation.

—Patsie L. Williams, LCSW-C
Chief, Div. of Developmental Disabilities, Baltimore County, Dept. of Public Health, Maryland

Correction: *The phone number listed for the Episcopal Church's Diocesan Office on Ministry with Persons with Handicaps was incorrect in the December 1994 issue. The number is (612) 721-1103.* EXCEPTIONAL PARENT *apologizes for the error.*

Religious Participation

How encouraging it was to read your December (1994) issue focusing on "Religious Participation for All." Your selection of authors covered a wide spectrum, and the clarity of their message is just right for us to share with religious leaders who are uninformed.

I particularly like the title of one article, "Catholic Life for Children with Disabilities." It implies more than services provided; our spirituality influences every aspect of life. Parents and siblings are renewed in their own faith when they see a person with a disability welcomed into their religious community. You have provided a vital service to families by encouraging them to see religious experience as an important part of all their lives.

—Sister Rita Baum
Ministry With People With Disabilities, Diocese of Palm Beach, Florida

☐ Congratulations for your courage in taking a great step forward and asserting the importance of "faith" as we attempt to address all areas of a person's life! What a beautiful link your magazine's issue on religious participation (December 1994) will be to educat-

Tell us about...

...talking to your child about his or her disability.

Write to: *Readers Talk,* EXCEPTIONAL PARENT, *209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

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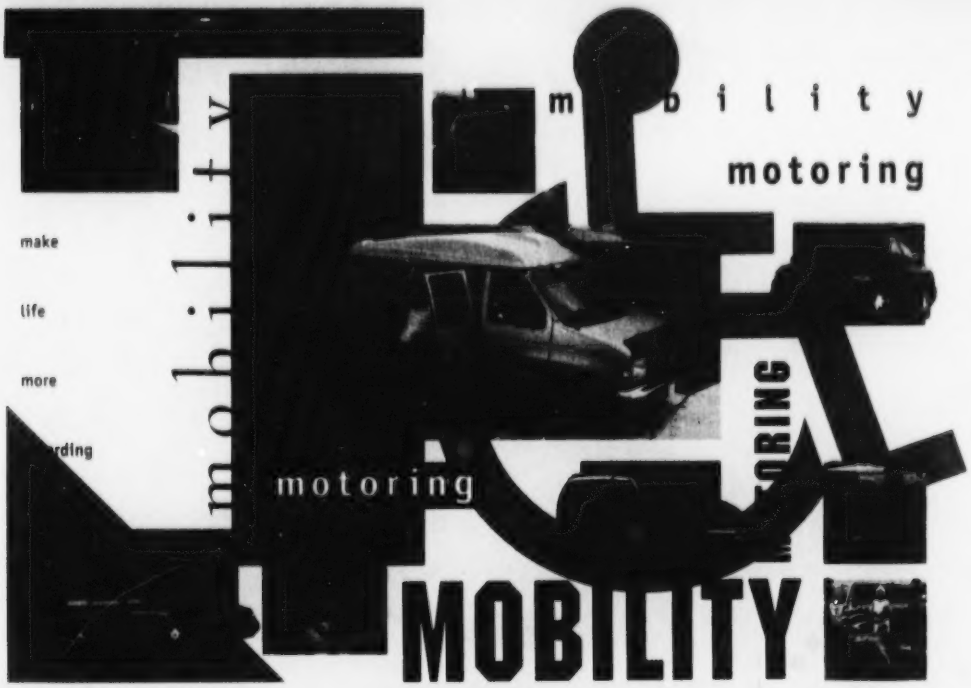

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ing professionals, parents, consumers and the community alike to the holistic needs of each person.

Kudos also to the committee chaired by the Rev. Bill Gaventa for taking the initiative to present the topic of religion with excellence.

As a parent of a beautiful 16-year-old daughter with disabilities (and also a professional), religion is the most integral part in my family's stability and growth.

Thank you on behalf of my family and the families we represent.

—Grace Bapst
Director of Church & Community Development, Agape Parents' Fellowship, New York

EDITOR'S NOTE: Agape Parents' Fellowship, based in Blasdell, NY, is an inter-denominational organization dedicated to parents and families of people with disabilities.

DO-IT

The DO-IT program, as described by Dr. Sheryl Burgstahler (November 1994), certainly seems to be an exciting program. However, missing from the program, or the article, is a description of the steps being taken to link these children with adaptive/assistive technology-related service providers in their communities.

In these times of shrinking federal programs, some sort of continuity must be ensured so these children have options when grant funding expires. It seems a bit cruel to turn these kids on to possibilities and then shut the door in their faces when federal funding is no longer available. This is particularly true for children in rural areas where technology exposure is minimal.

I certainly hope these issues are being considered by DO-IT as well as other disability-related federal programs.

—C.B, Washington

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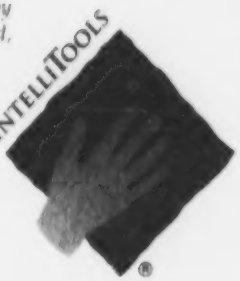

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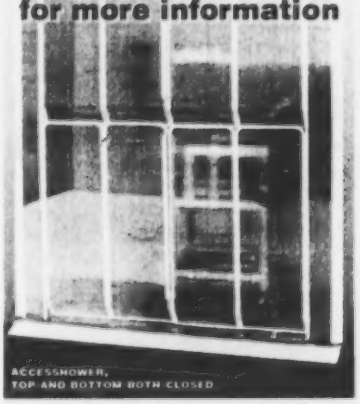

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SEARCH

Encephalocele/Microcephaly

Our two-year-old daughter, Emily, was born with microcephaly and an encephalocele on the top of her head. At three months, she had surgery to close the encephalocele. At seven months, she developed hydrocephalus and needed a VP-shunt. Emily also has a seizure disorder and bilateral optic nerve hypoplasia.

We are looking for a family who has a child like Emily or anyone else with information on this rare form of encephalocele.

J.H & T.H., Missouri

Krabbe Disease

My 16-month-old son, Troy Nathaniel, died in December 1992. He was diagnosed with Krabbe disease. All his genetic tests were normal. The doctors could not prove he had this disorder. They can't tell me if children I might have in the future will be affected by the same condition.

I want to know if anyone has had any experience with this condition. I don't trust the doctors' diagnosis and feel like they just gave up on my son.

R.M., North Carolina

EDITOR'S NOTE: The United Leukodystrophy Foundation (2304 Highland Dr., Sycamore, IL 60178, 800/728-5483) and the National Tay-Sachs and Allied Diseases Association (2001 Beacon St., Ste. 204, Brookline, MA 02146, 617/277-4463) can provide information about Krabbe disease and can put you in touch with other families.

Goldenhar Syndrome

I am the parent of a 14-month-old son, who has been diagnosed with Goldenhar syndrome, a cranio-facial disorder. Jordan was born with one eye, one ear, a mid-line cleft lip and palate, congenital heart defects, imperfections of the spine and skull malformations.

I am having trouble getting Jordan services; for example, he needs to be fitted with a glass eye. People are very cruel. I would like to correspond with a parent who has a child with Goldenhar syndrome or similar problems.

D.R., Saskatchewan, Canada

EDITOR'S NOTE: The 1995 EXCEPTIONAL PARENT RESOURCE GUIDE lists the following US group dealing with your son's condition: The Goldenhar Syndrome Research & Information Fund, 8829 Gleneagles Lane, Darien, IL 60561, (708) 910-3939.

In Canada, AboutFace (99 Crowns Lane, 3rd Fl., Toronto, ON M5R 3P4, 800/225-3223), a support group for individuals and families dealing with cranio-facial disorders, may be able to put you in touch with local resources.

AVM of the Vein of Galen

Our seven-year-old daughter was diagnosed at birth with a cerebral arteriovenous malformation (AVM) of the vein

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Circle # 16

of Galen. We want to hear from parents who have dealt with this type of AVM.

M.E. & O.E., Texas

Down Syndrome and ADHD?

Our four-and-a-half-year-old son, James, has Down syndrome. His teachers and other professionals consider him very high-functioning. At the same time, they say he may have attention deficit hyperactivity disorder (ADHD) because he is very active and always full of energy—a typical "class clown."

A psychologist who evaluated James six months ago thought he was too young to be put on Ritalin, but should be reevaluated in a year. We agree that James is active, but are not sure Ritalin or other drugs are appropriate. We are afraid of trading James' playful personality for a better-behaved child.

We are looking for anyone who has experience with a Down syndrome child who has also been diagnosed with ADHD. We have read everything we can find on ADHD, but as we all know, the rules change when the child also has Down syndrome.

J.G. & J.J., Ontario, Canada

EDITOR'S NOTE: Editorial Advisory Board member Siegfried M. Pueschel, M.D., Ph.D., M.P.H., responds: "My colleagues and I are following a number of children with Down syndrome who also have attention deficit hyperactivity disorder (ADHD). There is no reason why these two conditions cannot co-exist. However, it is important to make sure that environmental conditions, family stressors and/or emotional problems are not causing the observed problems. If not, and if behavior management approaches are not effective, one may consider "stimulant" medication, such as Ritalin or Dexedrine. A number of children with Down syndrome and true ADHD have responded well to Ritalin.

"In children with mental retardation, a diagnosis of ADHD should be made only if the child's attention skills and/or activity level are clearly inappropriate for his or her developmental level. If the decision is made to use Ritalin, one should start with a low dose and gradually increase the dosage if needed. It is important to monitor the child's behavior closely."

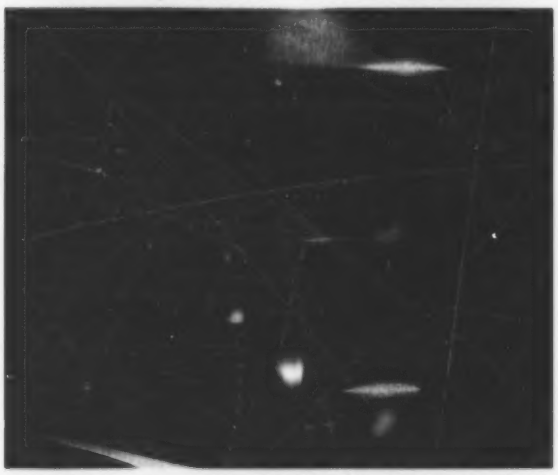
Search and **Respond** is an opportunity for readers to exchange information about their experiences meeting the everyday challenges of life with a child or young adult with a disability. *We also expect parents to ask appropriate professionals.*

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or **Respond**, ***Exceptional Parent,***
209 Harvard Street, Suite 303, Brookline, MA 02146-5006, Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

One of our most effective operating procedures requires the skillful use of these instruments.



Many of the children who come to Health Hill Hospital for rehabilitation have feeding problems in addition to other serious medical complications. They may be unable to drink from a bottle or eat from a spoon. So we've developed a program where a team of specialists in nursing, nutrition, occupational therapy, speech pathology and psychology work with a physician. Together, they devise a plan to teach the child to eat again. And because we believe the parents' involvement is vital, we teach them the skills needed as well. It's just one of the programs that help our children. And move them closer to going home. Health Hill Hospital For Children, 2801 Martin Luther King Jr. Drive, Cleveland, OH 44104. 216-721-5400.

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Circle # 185

RESPOND

Self-Catheterization

D.R. (October 1994) was looking for help for a friend whose 10-year-old daughter with spina bifida needed to learn how to catheterize herself. Her inability to self-catheterize limits her participation in spontaneous activities with friends and family.

I am an 11-year-old girl with spina bifida. I started doing self-catheterization when I was six or seven years old.

At first, I felt a little bit nervous. It was kind of embarrassing because I had to do it in front of the nurses, but it wasn't that hard. It did not take very long to learn—only two days!

I felt very happy to be able to do the catheterization by myself. I felt a lot better because I could go out and do more things. I did not have to stay home. Your friend's daughter can do it, too. I know she will do fine.

C.D., New York

☐ I want to recommend a wonderful booklet called *Toobie: A Self-Cath Coloring Book for Boys & Girls.* English and Spanish versions are available free from Mentor Urology, 5425 Hollister Ave., Santa Barbara, CA 93111. Write to them or call their customer service number, (800) 258-3480.

B.M.K., New Jersey

EDITOR'S NOTE: In addition to the free coloring book recommended above, Mentor Urology produces and sells other educational materials on intermittent self-catheterization. These include videotapes, flash cards and a parent guidebook.

Stepparent Seeks Insurance Information

M.S. (November 1994) has a five-year-old stepson with cerebral palsy, spina bifida and multiple, congenital, physical anomalies. Because Chris' father has left the military, Chris is no longer covered under the US military medical plan. Despite the fact that Chris' birth problems have all been corrected to the extent that they can be, his parents have been unable to find insurance companies that will cover him because of his "pre-existing conditions." M.S. wanted information on insurance plans that cover children with disabilities for the "normal" childhood illnesses and injuries. M.S. also wanted to correspond with parents who have a child with similar conditions, or other stepparents of children with any disability.

I, too, am the stepmother of a child with special needs. My nine-year-old stepdaughter, Robin, was born with a number of problems including severely clubbed feet, no anus, no bladder or urethra and a tethered spinal cord.

Being a stepparent is difficult in and of itself, let alone when there are complexities such as a child with disabili-

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Circle # 17

ties. There are few role models for stepparenting and I think the stepparent's role depends a lot on family circumstances. In our case, Robin travels back and forth between her parents' houses every few days, a schedule initially necessitated by her intense medical needs. My role is not as active as is it would be if Robin was with us full-time.

It has been a struggle for me to find my place. Robin has been very ill for about three of the four years since our marriage. She has had four major, unanticipated surgeries. There was a period when she was totally incapacitated with pain and no one could find a reason. All of these circumstances have put stress on my relationship with my husband and made it difficult for me to establish a relationship with Robin.

On the insurance front, I do have a couple of suggestions. The state of Wisconsin, where we live, runs a risk-sharing pool for individuals denied coverage by a commercial carrier. The premium is high, as is the deductible, but it provides coverage even for medical problems associated with a disability. Other states may have similar programs. Also, HMOs often accept individuals without a pre-existing condition limitation or medical certification, if coverage is part of a group policy.

C.M.E., Wisconsin

☐ As the parent of a child who has cerebral palsy, asthma and gastrointestinal problems, I also had difficulty finding insurance after his group policy expired. Like M.S., I live in California. I was fortunate to find the California Major Risk Medical Insurance Program, 818 K St., Ste. 200, Sacramento, CA 95814, (916) 324-4695 (voice), (916) 324-4878 (fax).

This program gave me a choice between five carriers with varying deductibles, benefits and pre-existing condition clauses (usually a three-month waiting period). Eligibility is based on proof that you or your child has been denied insurance coverage.

M.K., California

Disability Awareness in Public Schools

M.G. (October 1994) has a 10-year-old son, Allan, with Asperger syndrome (a type of "high-functioning" autism) and some neuromuscular problems. He does well in regular science and social studies classes. M.G. wanted to hear about disability-awareness programs that have been used successfully in public schools to teach kids about disabilities.

I am involved with an organization called Kids On The Block (KOTB). The "kids" are a troupe of almost life-size puppets, with and without disabilities, designed to teach school-aged children what it is like to have a disability or to be different.

Most KOTB troupes are manned by volunteer, community-based organizations. The program includes a teacher's manual, pre-performance activities for the children and follow-up. Some troupes offer performances dealing with a specific disability; others cover a range of topics.

KOTB troupes perform throughout the US, Canada and 20 other countries. You can obtain more information and a list of troupes in your area from the KOTB national office, 9385-C Gerwig Lane, Columbia, MD 21046, (800) 368-5437 (voice), (410) 290-9095 (voice), (410) 290-9358 (fax).

N.M., Ontario, Canada

All Together, Now!

by Justin Dart

WE WHO HAVE DISABILITIES and our loved ones are in grave danger of losing our fragile, hard-won beachhead on the mainland of American life. There is an escalating chorus of assaults on the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), Medicaid and SSI supports for children with disabilities. The new congressional leadership has announced their agenda—a "Contract with America"—that, if implemented literally, could drastically cut virtually all the programs that empower us. They speak of "erasing" key economic and social programs of the last three decades, and "reasserting American culture as it has existed for the last 300 years"—a culture in which people with disabilities were outcasts.

I cannot believe that the leaders of our nation—Republican or Democrat—are scheming to destroy our rights. But when I see the current eruption of public frustration with the growing pains of democracy, I remember history. I am terrified that the hysteria for instant solutions and easy scapegoats could result in a move to pull the plug on our progress, our rights, the programs that empower us and, in some cases, our very lives.

Justin Dart (left) speaks with President Bill Clinton about health care reform at the White House in May 1994.

Republican leaders have announced a blitz to pass their "Contract" agenda during the first 100 days. We must act quickly, while basic positions are still being formed.

Reach out to all of your state's representatives and senators. Nearly half of the current members of Congress were not present during the ADA debate in 1990. In too many cases, their perceptions of disability-related laws and programs have been formed during the recent avalanche of negative propaganda. Many Capitol Hill veterans, including old friends in both parties, have also been influenced by these messages.

Don't discount the potential support of new conservative members of Congress. Many are people of profound conscience, who share our passionate determination to emancipate all prisoners of dependency and empower them in the mainstream of free-enterprise democracy.

Our messages, our power

We have messages to deliver—to the Congress, but also to state houses, to the White House, to business, to labor and to groups representing minorities, women and older Americans.

There are many ways to deliver our messages—face-to-face or by telephone, fax, computer or mail. Use the media. Be visible at public events with signs and questions. Flood talk shows and newspaper letter columns. Communicate personal stories illustrating the necessity of the ADA and IDEA and their positive effects.

These are the messages we must deliver:

• *Disability impacts everyone.* Sooner or later, every family will experience disability. Public policy that fails people with disabilities fails every family. We who have disabilities form one fifth of the population—49 million Americans. Add in our families and service providers. We all vote.

• *The ADA is good for America.* The ADA is not a costly, unfunded mandate. It is a civil rights law that extends equal constitutional protections to Americans with disabilities. The ADA *will not* bankrupt anyone. It specifically provides that no business or public entity can be required to do anything resulting in undue hardship. The ADA *will* open the doors of opportunity, enabling us to get off welfare and into the productive mainstream. The ADA will pay for its tiny cost a hundred times in terms of reduced welfare and increased productivity.

• *No ADA amendment!* We will cooperate fully to ensure that ADA implementation is sensitive to the needs of individuals, businesses and communities. But we will fight any weakening amendment. We will fight for our right to be fully equal citizens.

• *Contract with America, Contract of the people, by the people and for the people—all the people—yes! Contract on Americans with disabilities, no!* Social and economic programs need improvement. No group is more aware of this than people with disabilities. But let us be careful that in our haste to change things, we do not create more welfare, more paternalism, more costs and more misery.

Let us ensure that changes protect and enhance all the programs and laws that empower people with disabilities of all ages to be productive participants in the mainstream. Let us ensure that changes empower people with very severe disabilities to be free from the fear of rationed life, to be emancipated from expensive, prison-like institutions and to live with dignity in their communities.

• *The American heritage at its best—the power of America's success, since 1776—has been the aggressive*

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159

read it monthly.

Dart (seated, third from left, wearing hat) joins other disability-rights activists heading toward the Lincoln Memorial as part of the "Bridge to Freedom March" for health care rights in May 1994.

empowerment of oppressed people to be fully equal participants in the mainstream of free-enterprise democracy. Nothing could be more Republican, nothing could be more Democratic, nothing could be more in harmony with family values, nothing could be more profitable, nothing could be more positively American than the empowerment of Americans with disabilities.

Unity

We have the ultimate weapons to win this battle for a just society. We have the moral and the economic arguments. We have people who have created miracles of independence and justice. We have each other.

If we can use the coming policy debate to establish principles of empowerment, if we can exploit the coming power struggles to create new political clout, if we can survive the coming test of fire with our principles and our passion intact, we will have established a foundation on which future generations in this and every country can build the edifice of democracy for people with disabilities.

We must set aside politics as usual, and unite in action—people with disabilities, family members and professionals. This will not be easy. Funding cuts invite cutthroat competition among us. The polarization of mainstream politics invites us to attack each other. Divide and conquer will be the strategy of our opponents. We must master the art of complementary unity, playing different roles in total harmony for the same goals—equality, independence and empowerment in the mainstream.

America is watching. The world is watching. Will our movement unite in action? Will we increase our advocacy enough to keep the dream alive? If we fail, God help our children in the 21st century when leaders say, "America tried equality for people with disabilities, and it didn't work. Why try it again?"

Justin Dart has founded and served as CEO of three successful businesses. A long-time, human-rights advocate, he has served five presidents in the area of disability policy. He recently resigned as chairman of the President's Committee on Employment of People with Disabilities to become a full-time advocate for the civil rights and empowerment of people with disabilities.

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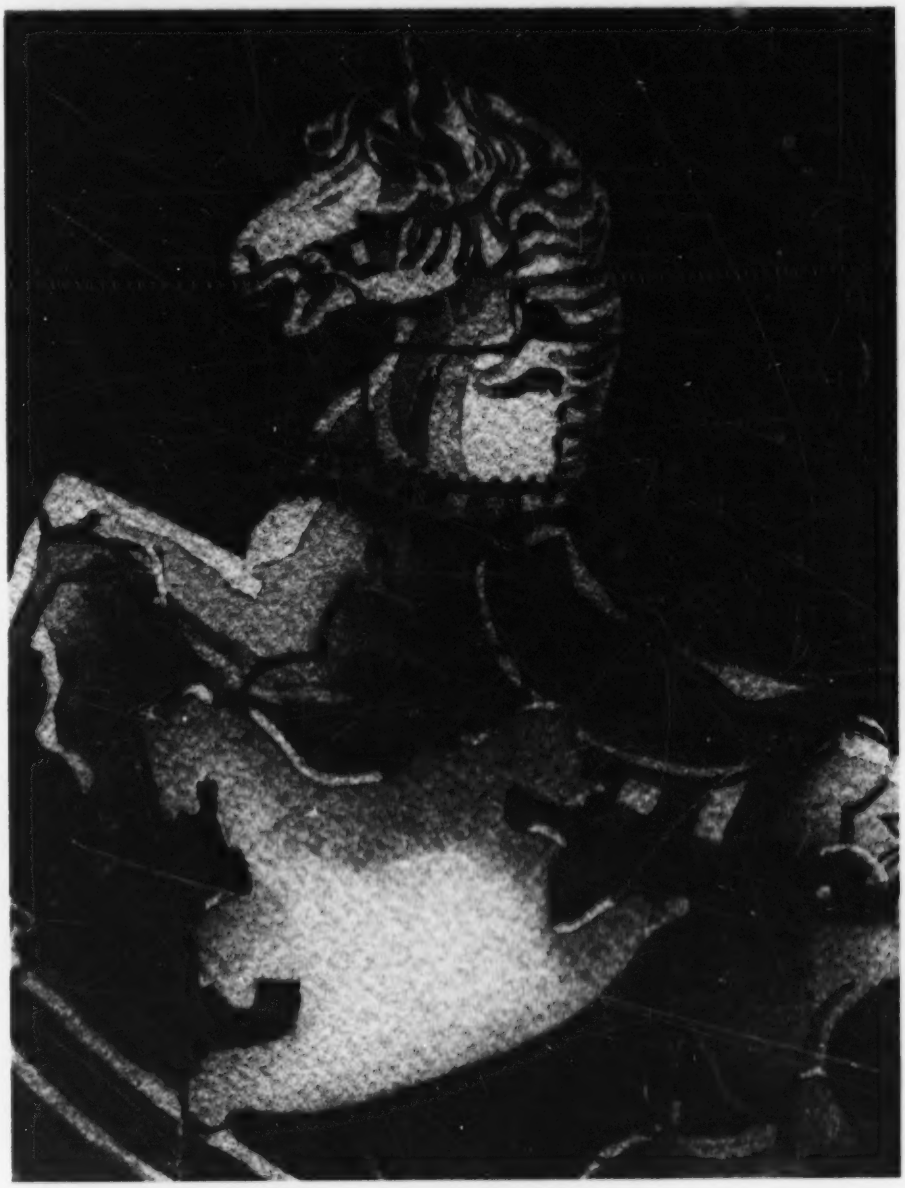

C U M B E R L A N D

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Circle # 74

My New Son

by Bob Maier

I feel so confused, hurt and utterly sad.
The child I thought was mine is gone.

I want to cry.
Cry for the child who will never ask, "Why?"
"Why do the leaves turn red in autumn?"
"Why do I have to go to bed right now?"
"Why are you crying, Daddy?"

Son, what will you be when you grow up?
I once thought you might be a zoologist,
traveling to exotic places,
studying the rare and wonderful animals
you've always loved.

When you were less than a year old, sitting
motionless,
listening to Mommy's choir sing,
I dreamt that someday you would be a
creator of beautiful music.

My child has been taken from me!
But that can't be.
He's here with me now.
He hasn't changed.
Yet still, I feel as though
he's gone.
My child has somehow
died.
The child of my dreams
and hopes is no
more.

I know these feelings are
normal and helpful,
that I shouldn't feel guilty
for having them.
All the experts tell me this.
But it doesn't help the pain.

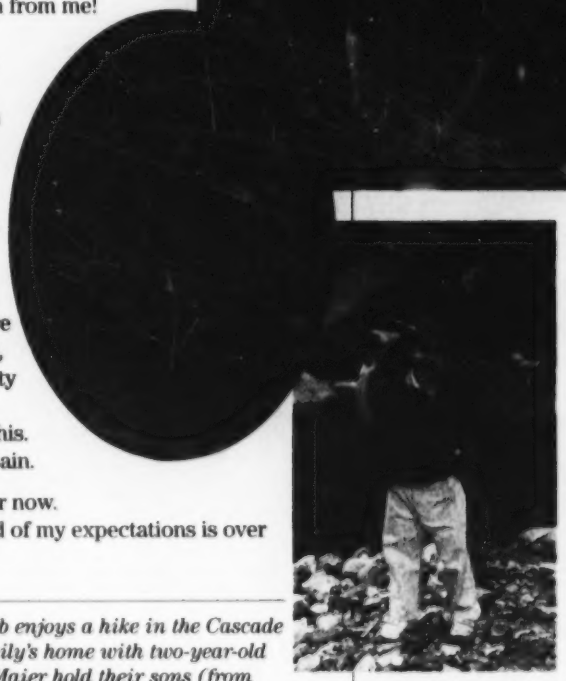
Things are getting better now.
The funeral for the child of my expectations is over
now.

Oh, I still visit the cemetery from time to time.
I put Cub Scout caps and grade-school science projects at
his grave.
But I don't spend so much time there anymore.

I have another son to love.
The one they call "autistic."
He's such a sweet boy.
He's never mean to anyone,
and he squeezes so
tight when he hugs me.
He loves to dance with his
daddy,
and he gets such a cute
smile on his face when
he says, "I did it!"

He's still the same boy who
loves monkeys,
Peter Pan, kiwi fruit and
throwing rocks in the
water.

I'm learning to love my new
son,
and he has always loved
me.



Bob Maier works as a fisheries biologist for the federal government. He lives with his wife, Deborah, and two sons—Karl, 6, and Keith, 4, in Edmonds, Washington. Bob wrote this poem soon after Karl was diagnosed with autism at age three.

Karl is now fully included, with the help of an aide, in a regular kindergarten class at his local elementary school. Recently, to his father's surprise and delight, he has started asking his first "why" questions.

Bob's favorite activity is picking blueberries with his family in the early autumn sun of the Cascade mountains near their home. Karl's favorite activity is bouncing on his trampoline while watching Disney videos.

[From top to bottom] Bob enjoys a hike in the Cascade mountains near the family's home with two-year-old Karl. Bob and Deborah Maier hold their sons (from left) Karl, 5, and Keith, 3. One of Karl's favorite pastimes is throwing rocks into the water of local streams and ponds.

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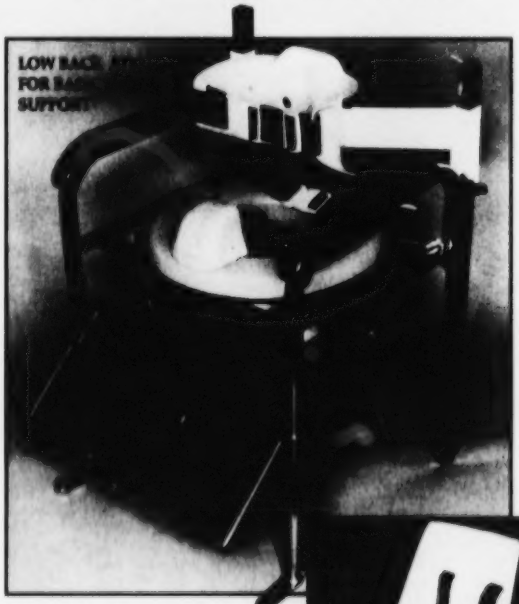

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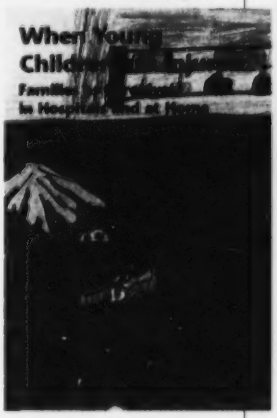
MEDIA

WHEN YOUNG CHILDREN ARE INJURED: FAMILIES AS CAREGIVERS IN HOSPITALS AND AT HOME by Marilyn Lash, M.S.W. and Jane Haltiwanger, M.A., Ed.M., is published by EXCEPTIONAL PARENT magazine and is available through Exceptional Parent Library (800/535-1910). It is the third in a series developed by the Research and Training Center in Rehabilitation and Childhood Trauma, Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center.



The guide has many examples that demonstrate that the family is the major support in a child's life before and after an injury. The following is an excerpt from Chapter 3, Helping Siblings: Needs and Reactions.

Suggestions for helping siblings

• **Stay in touch.** If hospital visits prevent you from seeing your other children daily, set up regular times to talk on the phone. If they are being cared for by others, send tape recordings of songs, bedtime stories or messages to them…

• **Make time for questions.** Siblings will have many questions, but they may not always ask them directly. They need someone to explain what has happened. It helps to repeat information, since changes are confusing and unsettling…

• **Keep explanations honest, simple and concrete.** When children ask questions that you don't know how to answer, let them know that you will find out. Then go back and explain in words they can understand. A good rule of thumb is to *give descriptions, not interpretations.*

For a child in a coma, instead of saying he is "peaceful" or "sleeping" or "can't hear," try saying, "His eyes are closed and he breathes very quietly. When I talk to him, he does not answer me." If a child asks, "Can he hear me?" you can answer honestly, "I'm not sure."

• **Communicate with teachers of siblings at school or day care.** Siblings need the support of their teachers and friends. Teachers will be more understanding and responsive when they are aware of the situation.

• **Include siblings in care.** You can teach siblings how to help… Even very young children can hand objects needed for care or open/close the curtains. Use actions and words that show a quiet, confident approach to touching, loving and caregiving. This helps siblings overcome their fears, reluctance or embarrassment.

FAMILIAR FACES

*"Isn't it ready yet?" A hungry **Theresa Marie Stevens**, 21 months, waits patiently for Mom to finish preparing her lunch. Theresa, who has cerebral palsy and epilepsy, lives in Port Royal, Virginia.*

***Ole Sorensen** (right), 12, shares a raft with **Victoria** and **Erika Houle** as the friends enjoy a summer day on Lake Superior at a beach near their Washburn, Wisconsin homes. Ole and Erika first met as HeadStart classmates; now Erika's mom is Ole's respite care provider. Ole has autism.*

*It must be puppy love! **Rachel Blecha**, 3, takes all the kisses she can get from her beagle puppy, Rose. Rachel, who has cerebral palsy, lives with her mom, dad and baby brother, Kyle, in Kewaskum, Wisconsin.*

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent?* Send it to: Readers' Photos, *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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During early childhood, children first confront challenges they will work on for the rest of their lives—interacting with the world, learning new things and getting along with others. All children, in all cultures, with or without disabilities, face the same developmental tasks. At the same time, each child draws on his or her individual strengths to meet these challenges. The stories and articles in this special section emphasize these two important messages—all kids need the same things, and all kids need different things.

To reach their full potential, all children need stimulating, caring environments where they can experience success and mastery. Many preschoolers will spend large amounts of time in a group care setting. Some articles in this section focus on child care options and the characteristics shared by successful programs. As each shows, nurturing caregivers are essential, but not sufficient—children also have individual needs requiring individual attention, even within a group care setting.

Meeting the specific needs of individual children means paying attention to issues of assessment and transition. "A New Vision for Assessment" and "Making the Transition to Group Care" provide guidelines and suggestions for these ongoing processes. Sidebars illustrate the successful results of careful attention to individual needs—inclusive child care that works for children with and without disabilities. (We are grateful to SpeciaLink, the Canadian network of inclusive child care providers, for sharing these stories with us. For more about SpeciaLink, see page 35.) "The Kindness of Strangers," demonstrates inclusive child care is important for parents, too. These stories also remind us that young children have much to teach adults.

This section includes an article about the Americans with Disabilities Act (ADA). People tend to think of the ADA as a civil rights and equal employment law for adults with disabilities. The ADA also benefits very young children.

The Kindness of Strangers

by Betty VanHoogmoed

Oh, this has got to stop! I had just picked up my son from daycare and as the center's supervisor began to brag about how well Jake was doing, my eyes welled up with tears. Again. But I just can't help it. The focus on my son used to be so negative. These positive, happy stories overwhelm me.

Undiagnosed

Jake has some sort of developmental problem, as yet undiagnosed. When he was a baby, doctors told us he was blind. Since then, although medical professionals still don't know why, his vision has gradually and miraculously improved. Jake is now two and a half years old; his visual acuity is much better, but he still does not walk or talk. He has some fine motor problems, too.

Understandably, Jake's problems have been a major focus for us, as well as for many medical experts, social workers, friends and relatives. In his short life, Jake has been examined by ophthalmologists, neurologists, geneticists, metabolics experts, dermatologists and audiologists.

My husband and I have filled out endless forms and repeatedly answered the same questions. My nine months of pregnancy have come under scrutiny, as has the past century of our relatives' health. Jake has been photographed, videotaped and examined some more.

Though we worried that Jake's many encounters with poking and prodding medical professionals would traumatize him in some way, the search for a diagnosis could not wait. Some conditions, especially metabolic disorders, could be successfully treated if diagnosed early.

With every test, we hoped we would get an answer. Once we had a diagnosis, we could do more for our son. We could read the literature on Jake's condition. Contact other families who have lived with it. Answer questions. Educate others. Get a glimpse into the future. The moment parents are given the name of a child's disorder—no matter how terrifying that diagnosis may be—they begin to deal with it.

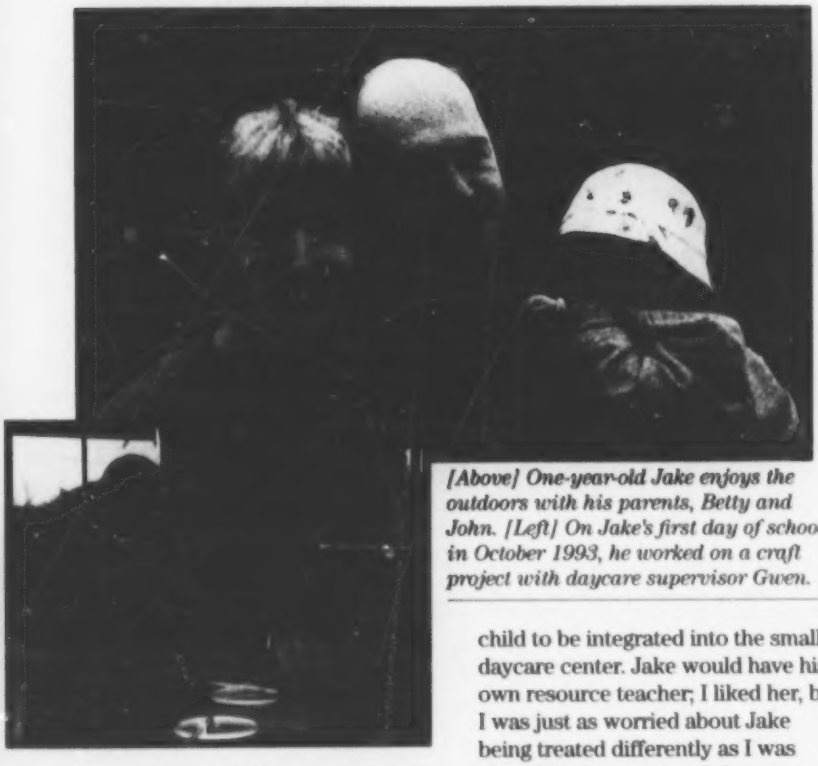
A "negative" focus

During the first two years of our child's life, it seemed that every interaction involving our son emphasized only the things he was unable to do. This negative focus came not only from doctors and social workers, but also from well-meaning strangers, relatives and friends—"What's wrong with him? Is he doing this yet? Have you tried this? When is he going to walk?" The questions and comments stemmed from concern, but they—as much as Jake's puzzling disorder—robbed us of the joy a new baby should bring to a home.

It was such a sad time—those first two years. We knew Jake had a problem but we didn't know what it was. We didn't know where to turn. We didn't know what to tell people. Access to services was often dependent on a diagnosis, which we obviously didn't have. We wanted an answer but we hated putting Jake through the testing. We needed help but resented the fact that we couldn't just close our front door and be a family. Living far from a major metropolitan center, support systems were minimal. I kept looking for people to help us, but nobody knew how. I wanted to talk about our experiences—but nobody understood.

In the midst of this swirling mass of questions was a little boy who puzzled, frightened or saddened those around him. Few people seemed able to enjoy him. Even I was obsessed with getting him to the next developmental phase. I loved my son and I played with him often, but teaching was always my motive.

Most people fell into one of two groups—knowledgeable professionals whose time, and often compassion, was extremely limited, and people who cared deeply about our little family but really didn't know how to help. The first ray of sunlight came last year. Jake's new physical therapist was the first professional who had ever seemed able to enjoy and help our son without being so bewildered about the nature of his disability. She accepted Jake just as he was, complimenting his wobbly stance while working on ways to improve it. As I watched her praise and play with him, I fought to control my tears. It was the first time I had seen professionalism meld with compassion, and the sight awed me.



[Above] One-year-old Jake enjoys the outdoors with his parents, Betty and John. [Left] On Jake's first day of school in October 1993, he worked on a craft project with daycare supervisor Gwen.

Beginning daycare

The second ray of sunlight turned out to be Jake's three-morning-a-week enrollment in daycare. The role of teacher/therapist/new mom had become too much for me. I felt so inadequate as the primary source of stimulation and guidance for my two-year-old son. Part-time daycare seemed like a good solution, but I was nervous about it.

Jake didn't trust many people—probably a result of all the medical testing he had endured. And he would be the first "special needs" child to be integrated into the small daycare center. Jake would have his own resource teacher; I liked her, but I was just as worried about Jake being treated differently as I was about him being treated the same.

I refused an assessment. I even withheld medical data—after all, he had no conclusive diagnosis. I just told his resource teacher to get to know him. She would discover the extent of his limitations soon enough.

In the beginning, Jake became very upset when I dropped him off. Once I could peel myself away from my sobbing child, I often stayed and watched through the one-way glass. And I liked what I saw.

Learning to trust

Before Jake started daycare, I cried many tears of frustration, rage and raw hurt. My tears had less to do with Jake than with my being thrust into such a new, frightening world and taking on the unfamiliar and very challenging role of teaching a child with disabilities.

Now, however, I am feeling stronger. The future looks more hopeful, and these days, the tears I shed are tears of happiness. The love of so many people for my son has softened my heart, and my tears. The kindness expressed toward him is so positive, so hopeful and so new.

I find myself overwhelmed by things most people take for granted. Witnessing the "real world" of childhood is so very touching—playing with toys, coloring, sharing, dressing up. All these common elements of childhood were, until now, so alien to my son, and to me. On the other side of the one-way glass, I often get teary-eyed when I see the children play. Not because my son isn't part of the activity—*but because he is.*

Give me an incompetent expert, an insensitive question or a tactless doctor and I'm ready. I've become quite a good fighter over the past two years.

But give me paper with paint splashed all over it and Jake's name at the top and I dissolve into a moist-eyed display of gratitude and wonderment. Tell me my son fed himself 10 french fries at lunch. Share a funny story about his participation in a game. Tell me how much the other children enjoy his company, and I can't hold back the tears.

My son is loved and cared for by people who were strangers just a few months ago. But what touches my heart the most—and gives me faith about the future—is that my son has finally learned trust.

And, looking back, I realize he isn't the only one.

Betty VanHoogmoed lives in northern Ontario, Canada with her husband, John, and their three children. Although you won't catch her baking cookies or trying to get her "whites even whiter," Betty describes her primary role as "mom" since hanging up a checkered career in media.

Jake, now three and a half, attends daycare five full days a week. He walks and is learning to communicate through sign language and some speech. His family and friends consider his lack of diagnosis secondary to everything else happening in his life.

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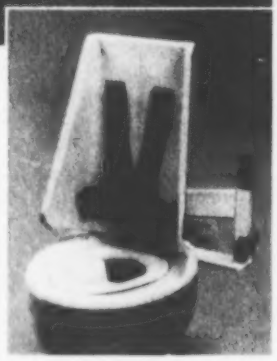

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Circle # 75

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A New Vision for Assessment

Choices about the best ways to serve the needs of young children and their families are made on the basis of a process called "assessment." The purpose of assessment is to learn about and understand the unique needs of each child "in context"—within his or her family, community and culture. In practical terms, this means deciding how to use resources most effectively to help each child grow and develop and to help his or her parents plan for the future.

ZERO TO THREE/National Center for Clinical Infant Programs, with the support of the A.L. Mailman Foundation, has convened a distinguished group of clinicians, researchers and parents to develop basic principles of assessment that can guide practicing professionals and enable parents to become more knowledgeable consumers. This article, written by Stanley I. Greenspan, M.D., Samuel Meisels, Ed.D. and the ZERO TO THREE Work Group, has been adapted with permission.

Developmental assessment is a process designed to deepen understanding of a child's abilities, and of the caregiving and learning environments most likely to help a child make fullest use of his or her developmental potential. Assessment should be an ongoing, collaborative process of systematic observation and analysis. It involves formulating questions, gathering information, sharing observations and interpreting information and observations to come up with new questions.

An assessment consists of a "snapshot," or series of snapshots (samples), of a child's knowledge, skills, abilities or personality characteristics. These snapshots are taken at a particular time, from a particular vantage point and with a particular instrument or recording device. An assessment approach that does not represent a child's day-to-day life will not be meaningful. This is particularly important with very young children, because the first three years of life are a period of such immense change, growth and development.

Limitations of current approaches

Under pressure to act quickly, professionals may approach assessment in a fragmented manner, rather than performing assessments that reflect full understanding of a young child and his or her relationships within the family, community and culture.

Under pressure to produce quick "scores," professionals may use procedures that were developed for older children. These can often yield misleading information. They are not built on a model of how the infant and young child develops within the family and do not reflect an understanding of the specific types of difficulties and developmental challenges that children and families face in the first three years.

There has also been a tendency to assess abilities easiest to measure—those for which there are tests already in existence. Assessments have traditionally put less emphasis on aspects of development that are hard to measure and have under-emphasized the social contexts within which a young child develops.

Assessments often overlook some abilities. This is especially true when a child has difficulties that may interfere with his or her demonstration of seemingly hidden strengths.

An assessment will be useful and accurate only if a child can demonstrate optimal abilities. This means allowing parents or other familiar adults to work with the child, using what they already know to discover more about the child's abilities and the challenges he or she is facing. Parents and professionals must observe the range of the child's skills in different contexts. The goal of assessment is not to test or to grade a child, but to learn how to best help.

Assessment should involve multiple sources of information and multiple components including:

- parents' description of a child's abilities in the different areas of development and discussions of their questions and concerns;
- parents' detailed description of a child's history;
- direct observation, including the child interacting with a caregiver;
- observations and discussions with the family about ways they have found to support the child's development and about family patterns that are of concern to them; and
- focused observations to assess specific abilities and disabilities.

This approach begins with information from family members, and then adds sources of information to help answer questions. This is very different from some approaches, in which professionals use a series of structured assessment tools (tests) to examine specific areas of development with only brief attempts to obtain a picture of the "whole" child by using information provided by family members or others.

ZERO TO THREE is the only national non-profit organization dedicated to improving the chances for healthy physical, cognitive, and social development of infants from birth to age three. Established in 1977, ZERO TO THREE is committed to:

- exercising leadership in communicating the importance of the first three years of life;
- focusing attention on infants' and toddlers' major relationships and on children's day-to-day experiences; and
- promoting training that helps service providers become and remain competent, trustworthy allies for families.

For more information about ZERO TO THREE's publications on assessment, early intervention and other topics, contact ZERO TO THREE, 2000 14th St. N, Ste. 380, Arlington, VA 22201-2500, (800) 899-4301.

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Appropriate approaches

• *The child's relationship and interactions with his or her most trusted caregiver(s) should form the cornerstone of any assessment.* A child's abilities should always be assessed in the context of interactions between child and caregiver—situations in which the child is most likely to feel secure and motivated and most likely to bring out the child's abilities.

Occasionally, the clinician may need to use his or her own interactions with the child as the basis for observations. But before the clinician interacts directly, he or she must take time to get to know the child and be sure the child feels comfortable.

• *Understanding the sequences and timetables of typical development is essential.* The period from birth to three is one of rapid physical growth and change. While maturation generally proceeds in an orderly and predictable sequence, there is a considerable range in what can be regarded as normal or typical. There may be considerable variation in the characteristics of a particular skill and the age at which it first appears.

To understand where a child is in his or her development, clinicians (and parents) need to have a broad sense of the sequence (what precedes what) and timetable (the age range during which one can expect to see an ability emerge) for different areas of development. Understanding where a child is in terms of sequence and expected timetable enables adults to predict what will come next and to determine whether a skill is emerging more slowly than expected. This is better than using a "score" or "quotient" to describe a child's abilities because it allows the use of many sources of information in formulating an intervention plan.

Including Kaylee

Increasingly, children with special health care needs are attending regular daycare centers. Staff members must learn new skills to care for these children—from monitoring food intake to more complicated medical procedures like catheterization, administering oxygen or changing a colostomy bag.

At the Burquitlan Childcare Centre, we first faced the challenge of including a child with special health care needs when we met Kaylee.

Kaylee was a three-year-old child with a tracheostomy—a breathing tube through her trachea that ended with a hole in her neck, covered with a removable cap the children called a "nose."

We've always felt that when a family arrives at your doorstep, you do your best to help them. Kaylee was a child who needed exactly what we had to offer—a good daycare setting. But her tracheostomy was one need we had *not* been trained to deal with.

The daycare center is far from a sterile hospital setting. It's full of messy, active activities—sand, water, paint and a lot of outdoor play. Kaylee was a very mobile child who was physically able to participate in all the usual activities. Compounding the challenge were the other children who were sure to be curious; we worried that another child might pull Kaylee's "nose" just to see what would happen.

Including Kaylee meant more than simply dealing with the child. We knew we would have to deal with staff training and concerns, parental expectations, liability issues and the curiosity of the other children. It took a lot of reassurance from Kaylee's parents and doctors and the Alberta nursery school she had previously attended to give us the courage we needed.

Staff training

Kaylee's parents and doctors insisted that non-medical personnel could handle routine trach procedures. As an introduction, her mother demonstrated the procedures to our staff. A nurse came to the center for a more in-depth discussion. Then we went to the hospital to observe and learn the procedures.

We decided on some fundamental rules for quality practices. For example, no second-hand knowledge was allowed. That meant one staff member would not train another to care for the trach. Training always meant going back to the source—to medical professionals.

Parents and children

Kaylee's parents wanted her to feel like a typical child with a trach, not like a "trach child." Their attitude had a lot to do with her attitude, and with our attitudes as well.

We thought about what we should tell the other children before Kaylee arrived. We finally decided that it was like "Johnny wears glasses"—you don't warn kids ahead of time that Johnny's glasses can break. We decided they only needed to know that the tube doesn't hurt Kaylee, but that they shouldn't touch it and had to be careful when playing with her in the sandbox. Kaylee wore a bandanna over the "nose" when she played in the sandbox. Soon, all the kids wore bandannas in the sandbox.

Kaylee's trach had to be cleaned several times a day, first instilled (using a saline solution from a syringe to loosen mucus) and then suctioned. Staff did these procedures in the daycare office.

Suctioning is noisy and messy—it's just like blowing any child's nose. At first Kaylee didn't want anyone to watch. But soon she was comfortable enough to have her friends accompany her to the office. They would continue their conversations while we cleaned her trach. It wasn't long before all the kids were suctioning their dolls.

Staff members agree that the extra work it took to include Kaylee was well worth it. Kaylee is currently in kindergarten. She has age-appropriate social skills because she had typical childhood experiences. And because an inclusive daycare program was available, her parents were able to keep up their careers.

—Trudy Norton and Aly Prins

Trudy Norton and Aly Prins are co-directors of the Burquitlan Childcare Centre in Coquitlam, British Columbia, Canada.

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Professionals assessing a child must have sufficient experience with observing a wide range of infants and toddlers and their families. Only professionals with an excellent understanding of early development should be given responsibility for assessments that will lead to a determination of a child's developmental status and/or a plan for intervention.

• *The assessment process should identify the child's current abilities and strengths, as well as abilities the child needs to develop to attain landmarks further along the developmental road map.* Development proceeds in a stepwise fashion; one capacity builds on another. Our knowledge of the typical timetable for skill development can be useful. It can never be useful, however, to describe a child as being a certain number of "months behind."

• *Assessment should be an ongoing collaborative process between professionals and parents.* Participation should be open to everyone who is substantially involved in supporting the child and family. Parents and significant caregivers, members of a family's support networks and professionals with special expertise all have important roles to play.

• *The process of assessment should be viewed as the first step in a potential intervention process.* A working alliance between parents and professionals who agree about the child's strengths, vulnerabilities and challenges is essential to identifying and planning ways to support a child's continuing development.

The rapid changes that typically occur in the first three years of life make ongoing monitoring and frequent reassessment important. Careful observation of the child in multiple but familiar contexts and on multiple occasions will provide a rich picture of the child's current strengths and challenges.

When a child and family are involved in early intervention, professionals and parents should meet regularly to compare observations of their day-to-day experiences. These discussions will help team members identify new goals and promising ways to approach them.

Inclusive Child Care Benefits All Children

When my son, Scott, was four years old, he met a new friend at daycare. Quickly, Scott and James became inseparable best buddies. Although Scott talked a lot about James at home, we didn't realize James was blind until we went to a parents' meeting two months later.

I guess we should have known something was different. Scott, has always been a rough-and-tumble type of kid—not terribly interested in quiet, indoor play. His interests had always been physical—running faster, jumping higher, throwing further. But now, Scott was coming home and talking about listening—picking up the sounds of squeaking hinges or of juice being poured. He told us it was neat to use sounds to try to guess what was happening when you closed your eyes. He said James could do that real well. Scott said James wanted to be an air conditioner repairman when he grew up; now, so did Scott.

At the end of that year, James moved away. It's been four years since the boys were together. But we continue to be amazed at the combination of "tough guy" in Scott, and the care and interest he shows for people with disabilities. It's as though he very naturally sees past their disabilities, as though he sees the inner person right away. We think we have James to thank.

Having experienced the benefits of inclusive child care, we now participate in protests and letter-writing campaigns to get children with disabilities into the classrooms and summer recreation programs our children attend—we now know that experience is valuable for everyone.

—Edward Roberts

Inappropriate approaches

Some current practices have no place in an ongoing, collaborative assessment process:

• *Young children should never be challenged during assessment by separation from their parents or familiar caregivers.*

• *Young children should never be challenged by assessment by a stranger.* Unfortunately, in many settings where assessments take place, very young children are introduced to strangers and, after only a brief "warm-up" period, are expected to demonstrate their "best abilities." This is highly unlikely to yield meaningful information.

• *Formal tests should not be the cornerstone of an assessment.* Many assessments are conducted using tests that have been chosen only because they are available, or because available staff have been trained in their use. Structured tests look at what an infant can and cannot do in relationship to defined procedures. The abilities tested by formal tests are only approximations of skills the child needs to use in real-world situations; natural observations are more useful.

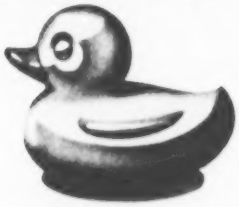
Many tests were developed with children who were not experiencing developmental challenges. These tests are not designed to bring out the unique abilities and potential of children with disabilities.

Conclusions drawn from misleading scores may lead to inappropriate recommendations. Compared to complete assessments of infants and toddlers with disabilities, test results often seriously underestimate children's true capacities.

Summary

The cornerstone of assessment should be observations of the child with trusted caregivers. Assessment involves multiple sources of information, organized and integrated to obtain a picture of the "whole" child. Appropriate assessments should help parents and professionals deepen their shared understanding of a child's competencies, and of the caregiving and learning environments most likely to help the child make full use of his or her developmental potential.

"It takes one look into their eyes to understand. Medically fragile children need a special kind of love. Right at Home."



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Circle # 165

Daycare for Children Who are Medically Fragile

By Wanda Monical

Here's a typical morning for Ellen and her family. Her parents are up at 5:30 a.m. Her mother packs the diaper bag and other essentials for daycare. She wakes Ellen at six for bathing and dressing. Ellen slept fitfully last night. So did the rest of the family.

Meanwhile, Ellen's father starts breakfast—making a special one for Ellen—and wakes Jenny, Ellen's older sister.

What makes this typical morning different are the "other essentials" in Ellen's diaper bag. There's not only a change of clothes, but her feeding pump, tubing, syringes, medications and a special formula. Ellen's "daycare" is staffed by nurses and therapists, as well as teachers.

Two-year-old Ellen has cerebral palsy and gastroesophageal reflux. She has difficulty eating and is unable to hold her head up by herself. Until six months ago, nurses and therapists were in and out of the family's home on a constant basis.

Photo courtesy Olsten Kimberly QualityCare, Auburn, MA.

The family lost a needed second income and insurance benefits for Ellen when her mother had to quit her job to care for Ellen. The family felt isolated and powerless.

Ellen's family is not alone. There are more than three million children with chronic illnesses and disabilities who need complicated care. This number is growing as major medical advances increase the survival rate of high-risk infants.

Families struggling to meet the needs of these children often find themselves overwhelmed. Homes become makeshift hospitals and parents become nurses. Parents never leave the kids, and often lose sleep because of the around-the-clock care the children require. The physical drain, financial pressure and isolation can have devastating effects on a family.

An alternative for families

Medical daycare or day-treatment centers offer an alternative for these children and their families. Although only a handful of these centers are now in operation in the country, interest is growing.

Typical centers operate Monday–Friday from 7 a.m. to 7 p.m. Some offer after-school, weekend and respite services. Most feature indoor and outdoor play areas, separate infant and toddler sleeping rooms, educational activities and therapies. Decors are bright, friendly and resemble typical daycare settings. Nursing stations and treatment rooms are the only obvious indications of a controlled, clinical environment.

Most centers accept children with a developmental age of less than six years who are considered medically complex, require skilled nursing interventions and are technology dependent. Diagnoses may include failure to thrive, multiple congenital anomalies, respiratory conditions, cancer, cardiac disease or other conditions.

Some centers offer care to children with less complicated medical conditions such as those requiring only cardiac-respiratory monitoring. Additionally, "typical" children may also be integrated into the program to promote peer relationships and acceptance.

Medical models

These centers are medical models, meaning they are staffed by nurses specializing in pediatric and neonatal care; physical, occupational and speech therapists; child-life specialists and medical social workers. Some centers also include respiratory therapists.

An average 3:1 child-to-staff ratio is typical, depending on a particular child's needs. Many high-tech therapies can be provided on-site with

Medical Daycare Centers

Children's Express, Columbus, OH, (614) 461-2727. *Six weeks to five years; capacity of 20. Circle # 187*

The HUG Center, Atlanta, GA, (404) 393-9222. *Birth to five years; capacity of 18. Circle # 188*

KennedyKids, Kennesaw, GA, (404) 499-7291. *Six weeks to six years with capacity of 18. Circle # 189*

KidStreet, Denver, CO, (303) 894-0401. *Six weeks to six years; capacity of 10. Circle # 190*

Olsten Kimberly QualityCare's Center for Medically Complex & Technology Dependent Children Auburn, MA, (508) 721-2626. *Four weeks to seven years, capacity 24. Circle # 191*

Child Health Systems, Westwood, MA, (800) 237-2474. *Operates five day centers in Florida (Tampa, Orlando, Miami, W. Palm Beach and St. Petersburg) and two in Massachusetts (Brookline and Waltham). Birth to 21 years in Florida; four weeks to seven years in Massachusetts. Circle # 192*

SpecialCare of Tucker, Inc., Chamblee, GA, (404) 458-5970. *An educational model providing therapeutic services from birth to age 21. Circle # 193*

Voorhees Pediatric Facility Voorhees, NJ, (609) 346-3300. *Opening March 1995. Birth to 21 years; capacity 27. Circle # 194*

Note: Use circle numbers on "Free Product and Information Card," page 47.

some centers housing their own pharmacy. Medical equipment designed for home and alternate site use can also be accommodated. Developmental therapies—including physical, occupational and speech therapies—can be provided in group-based, day-to-day activities and individualized sessions.

Centers are licensed by state day-care licensing authorities or PPEC (Physician Prescribed Extended Care, licensing agencies recognized in some states, including Florida and Delaware). Most centers are located in community-based settings, making transportation more convenient. Some centers can arrange transportation to and from home or school.

Self-confidence and acceptance

Early childhood education and/or child-life services are all a part of caring for the child. These centers promote self-confidence and acceptance, and prepare children for a smoother transition into the community school system by emphasizing social, emotional and intellectual development as well as normal growth and developmental tasks such as toilet training, feeding and motor skills.

Photo courtesy Child Health Systems, Westwood, MA.

Cost-effective care

As managed care gains momentum, hospital stays are shortened and more care is shifted to families and community-based providers. The need for more cost-effective alternate-care settings is growing. A child can attend one of these centers at a cost that is about 25–30 percent less than traditional home-care nursing (which already is a fraction of the cost of hospitalization). This does not include the savings from decreased rehospitalizations, earlier hospital discharges and the fact that children who are medically complex progress more rapidly in a stimulating, clinically-structured environment.

For parents of children who are considered medically fragile, the struggle to find special daycare services is extremely difficult. This exciting new model gives families and children not only a sense of control, but a sense of normalization.

Wanda Monical has worked in the health care field for 15 years and is the founder of Home Care Solutions, an Atlanta-based consulting firm specializing in new business development and alternate site delivery centers.

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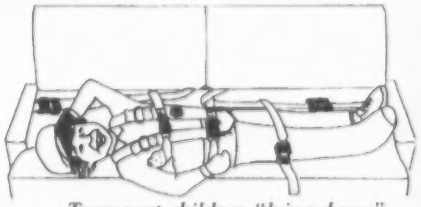

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Circle # 194 173

Making the Transition to Group Care

by Mary M. Donegan, Dale B. Fink, Susan A. Fowler and Michael W. Wischnowski

An important milestone in any young child's life is the start of attendance in a group care setting. In earlier generations, this step was usually associated with the beginning of first grade or kindergarten. In North America in the 1990s, this is no longer the case; most children now attend some kind of half- or full-day daycare prior to kindergarten.

Families as well as staff working in early childhood and early intervention programs have come to recognize the entrance into such programs as a period of adjustment for many young children and their parents. This article presents strategies that may ease adjustment problems and decrease the amount of time required for a young child to make a successful adjustment to the new setting:

- **Begin early:** Advance planning allows parents enough time to prepare the child as well as themselves. This also assures there will be adequate time to search for a setting that is the least restrictive and most appropriate.
- **Talk about the new setting in positive ways:** Equating transition with getting to be a "big boy" or "big girl" and showing pride in the child's increasing maturity and independence helps the child focus on the positive aspects of this change. Sometimes referred to as *positive forecasting*, this helps the child begin to anticipate what to expect in the near future. Another way of presenting the new setting in a positive light is to spend time with the child looking at a copy of a brochure from the new program, particularly if it contains photographs of the building, the classrooms, smiling children and affectionate teachers. Some programs have produced

Joey Gave Us the Tools

Daycare workers who are committed to inclusion have plenty of experience facing tough challenges. We learn sign language. We adapt physical settings to accommodate wheelchairs. We take on medical responsibilities not typically considered part of daycare work.

But Michael, a child with autism/PDD (pervasive developmental disorder), brought a whole new set of challenges to the University of Winnipeg Students' Association Daycare.

Compared to Michael, adapting our program for a child with cerebral palsy or Down syndrome had been easy. Michael made limited eye contact, fixated on toys or other objects for hours and had difficulty coping with even small changes in his environment. Just moving a table could cause him to scream and flap his arms and withdraw for days.

We wanted to include Michael but knew we needed some help. Fortunately, we found Joey Kneisz, a psychiatric nurse with Preschool Consultation, part of the Manitoba-based Autism Services program. Joey gave us the tools to help Michael learn to anticipate, make choices and participate in activities. Stressing the importance of structure, routine and repetition, Joey recommended specific strategies:

1. Have a written script—literally, a plan for every period in Michael's day.
2. Use a "routine minder"—a photographic guide to Michael's daily schedule.
3. Carefully prepare Michael for each transition or change.
4. Integrate Michael into highly predictable activities one at a time and let him learn each one well.
5. Slowly bring other children into the routines of Michael's day.
6. Build on Michael's comfortable activities to broaden his horizons.

I began by working one-to-one with Michael in a quiet area. Every morning, Michael's mother reminded him he would see me and showed him my picture. Then, in the privacy of the quiet area, using the same words and pictures every day, his mom and I would prepare him for her leaving.

Soon, we were able to take the first steps to include Michael with other children. We started with morning Sing-Song time. Since we wanted Michael to be part of Sing-Song, we had to plan songs in advance. Now, we always start the day with the same "Good Morning" song, followed by the same alphabet song and then a song we call "Michael, Michael, Woo, Michael." After three songs, Michael leaves and has a snack. We discovered the other children also enjoy the predictability of the first three songs.

Our next goal was to bring another child into Michael's private day. After snack, Michael and I always worked together on a puzzle while other children played nearby. One child, who was interested in the activity and seemed to have skills that would help Michael, was invited to join. I helped Michael rehearse for this child's inclusion by telling him the girl's name and showing him her picture. After several days of her participation, Michael showed interest in her when she appeared. Now, other children have also been recruited to join Michael's activities. And by carefully adding components of the unfamiliar to the familiar, Michael's participation in regular daycare activities has increased.

Difficulties remain. Events sometimes counter attempts to make Michael's day predictable. The fire alarm may go off unexpectedly or another child may be absent. But by using scripting, rehearsal and routine, Michael has been reached and is gaining a repertoire for social interaction.

—Merilyn Renaud

Merilyn Renaud is a special needs facilitator in Winnipeg, Manitoba, Canada.

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videos that can be shared.

Helping the child shop for a new book bag, backpack or lunch box—which will not be used until the first day of the new program—can present another opportunity for positive forecasting.

• **Encourage the child to ask questions and express fears:** Be accepting of a child's worries, rather than dismissing or making light of these feelings. For example, if a child says he won't go to the new program unless his brother or sister also goes, an adult can say something like, "We will miss you, too. We will be waiting for you when school is over."

Use dramatic play and storybooks to anticipate upcoming changes. Pretend play can help children deal with fears as they pretend to take a bus or find their cubby at the new school. Parents and children can share storybooks in which a child starts school or goes to daycare for the first time. Such books can help children understand that it is all right to feel sad and afraid, but also that things usually work out just fine.

• **Engage the child in group experiences:** Children who have had no previous large-group experiences, will benefit from exposure to groups of children in new environments. Activities such as story hour at the local library can provide good large-group experiences.

It may also be possible to arrange play dates in advance with one or two of the other children who will be attending the program. Knowing at least one other child's name and face before entering the new environment will help the child look forward to the experience.

Arrange visits to meet teachers and to observe or join in classroom and playground activities. Plan the first visit for a time when fewer children will be there so the child can explore the classroom and become familiar with staff.

Help the child identify similarities and differences between current surroundings and the new program. For example, an adult may point out that the new school has a slide just like the one at the park. If possible, videotape activities and be sure to include close-ups of staff members. Show the video at home.

Whenever possible, give your child the opportunity to make some real choices. For example, if the transition involves leaving another program, let the child choose a special treat to bring for the staff and the other children in that program.

In preparing for the new program, let the child choose a toy or other object that can travel back and forth from home with him and sit in his cubby during the school day. A favorite toy or family photograph is familiar and comforting to the child; it also gives the child something to talk about with his new caregivers.

• **Teach useful skills and routines:** Children can benefit from opportunities to learn and practice independent skills that are considered important in the new environment. Observations of the classroom routine and discussions with staff members can help parents and therapists determine skills the child will need to function as independently as possible.

Practice selected classroom "survival skills" throughout the year or a few months before the transition. For example, putting toys away after playing with them can be taught all year long. However, skills more specific to the new program—for example, sitting on a carpet square for circle time—may be introduced shortly before the transition.

It is very helpful to find out in advance how daily routines such as bathroom, nap time and transitions between activities are handled. For example:

• Are children taken to the bathroom as a group? Are they expected to tell the teacher on their own when they need to go?

• If there is a nap time, is the child expected to recognize his own blanket or find her own name on a cot? Is the child expected to carry a cot to a designated spot?

• How does the teacher indicate that it is time to come inside when children have been out on the playground? Do they form a line? Are the same cues used for transitions before or after other activities?

Before the child enters the program, it is important to inform the staff about the child's progress in mastering skills needed to function independently. This is especially

Sharing Confidential Information?

Sharing information among the programs that serve a child with special needs and forwarding records to new service providers are key ingredients to ensuring a timely transition and easing a child's adjustment. Providing new program staff with up-to-date information about a child's abilities and disabilities can educate new caregivers, prevent unnecessary duplication of services and ensure that children will be able to get the most from a new program. However, parents and staff often have concerns regarding how much, when and what type of information should be shared. This is especially true when a child with special needs is entering a program where most of the other children are perceived as "typical."

Families of children with disabilities may fear that sharing their child's diagnosis or other confidential information may result in lower expectations on the part of the staff. Some parents fear that the child will be stigmatized. Staff may have their own concerns about balancing parents' and children's rights to privacy with the need to share information that could ease a child's adjustment.

Some parents use a wait-and-see approach—they provide information only as events make the information relevant or helpful. While this approach allows parents some control, it may delay the sharing of important information. Some programs expect parents to sign release forms before transition planning occurs. These forms allow program directors to decide when and if specific staff members need access to the information.

This is not an easy issue. How have you dealt with these requests? We'd appreciate hearing about your experiences and perspectives. Write to us at FACTS/LRE, University of Illinois at Urbana-Champaign, 61 Children's Research Center, 51 Gerty Dr., Champaign, IL 61820.

—Mary M. Donegan and Dale Fink

important if the new environment is a regular early childhood setting in which the child will be one of only a few children with special needs. To ensure continuity and success for the child, it will be important to arrange for program staff to support and continue instructing the child in these skills.

• **Communicate and share information in advance:** Parents or therapists may be able to demonstrate positioning, handling or feeding techniques. They may also be able to inform the child's new teachers about ways to prevent or deal effectively with difficult behaviors.

It is also useful to discuss rules regarding privacy and confidentiality (see sidebar on page 30). How much information should be shared with staff members? How much information should be given to parents of other children?

Working together, parents, members of the child's team and staff of the new program can assist children and families in developing a sense of comfort and trust in the new setting.

This article was adapted from a publication of FACTS/LRE (Family and Child Transitions into Least Restrictive Environments), a federally-funded outreach project of the Office of Special Education Programs, US Department of Education. Susan A. Fowler, Ph.D. is project director, Dale B. Fink is project coordinator, and Mary M. Donegan and Michael W. Wischnowski are associates. Fink, Donegan and Wischnowski are doctoral candidates in the Department of Special Education, University of Illinois at Urbana-Champaign; Fowler is department head.

The booklet from which this article was adapted, ENTERING A NEW PRESCHOOL: HOW SERVICE PROVIDERS AND FAMILIES CAN EASE THE TRANSITIONS OF CHILDREN TURNING THREE WHO HAVE SPECIAL NEEDS, *can be ordered from IRHD Publications, 61 Children's Research Center, 51 Gerty Dr., Champaign, IL 61802. The cost is $2.50; make checks out to "University of Illinois." You may also write for more information about FACTS/LRE and an order form listing all project publications.*

Brandon was once filled with rage. He pinched, kicked, bit, and scratched the people he loved, often hurting himself in the process.

His anger was understandable. Blind since birth, having cerebral palsy, and other developmental disabilities, Brandon had great difficulty performing even the simplest tasks. He wanted independence, but could barely communicate even his most basic needs.

After making limited progress at a school for the visually impaired, Brandon came to Heartspring. An interdisciplinary team of Heartspring specialists explored his specific challenges and began the process of helping Brandon to learn more acceptable ways of expressing his wants and needs.

Rather than angrily acting out his frustration, Brandon learned to ask for help — with the assistance of a communication device when necessary. He was given positive reinforcement with each step forward. He was given love always.

Before long, a wonderful young man began to develop. Embracing the new possibilities in his life, Brandon learned new orientation and mobility skills so he can go by himself from his classroom to lunch everyday and many other places at home and on campus. He now takes the school bus home on Fridays to spend time with his family. Down the road, Brandon will return home and to his public school. We want to help him with that journey.

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Circle # 3

Readers Talk About: CHILD CARE

A few months ago, we asked readers to tell us about their experiences finding child care for young children with disabilities. Here are some of the stories they shared...

"Friends, Mommy. Friends"

Our third child, Joey, who has Down syndrome, began daycare at a center for children with disabilities when he was 10 weeks old. When Joey was almost two, a staff member suggested that he move to a regular daycare center. I thought any center would beg to accept my son in order to enrich the lives of the other children. Ten phone calls later, I realized it wasn't that simple. Most were not interested in "the challenge." Others promised to call back, but never did.

Finally, I called the area director of the Discovery Schools. I told him a little about Joey—he signed more than he spoke, was physically awkward and had not yet mastered the art of feeding himself with a spoon.

Joey (left) participates in a Halloween costume parade at the Discovery School daycare center.

I waited for the inevitable silence, but there was none. Instead, I was assured that the chain had a policy of non-discrimination and would be happy to accept Joey.

We had cleared the first hurdle, but how would the actual staff respond? Starting with our first visit, the teachers who would be working with Joey were eager and interested. Because they did not know sign language, they asked to have his speech therapist teach them the signs he used.

As Joey moved from the infant to the toddler class, we watched him bloom. Eating lunch with other children did more to encourage him to feed himself than everything we'd tried at home. The teachers labored with Joey over his attempts to paint and hold scissors and facilitated his interaction with the other children.

Last September, at age four, Joey advanced to the preschool class. Although potty-training was a prerequisite for this class—a milestone Joey had not yet achieved—the staff recognized his need to be with his peers.

A few weeks ago I arrived at the center to pick Joey up. The children were outside on the playground, so I went in to collect Joey's things. In his cubby, under the day's artwork, lay a small, white envelope. Heart pounding, I opened it to find an invitation to a classmate's birthday party.

Outside, I found Joey climbing the monkey bars with two other boys. He greeted me, then motioned enthusiastically to his companions. "Friends, Mommy. Friends," he said happily. And I thanked God for Discovery School.

—Teresa L. Nelson
Mechanicsburg, Pennsylvania

Surprise Visits

Although my husband and I were uncomfortable placing our four-year-old son with Lennox-Gastaut syndrome, into daycare, we had no choice. I had to work and my mother—who had been caring for Craig—had passed away.

We knew it wouldn't be easy finding an appropriate program. We finally decided on a center where he would be the only child with special needs. I chose this program because it was very small.

Within a month, I had become quite unhappy with many aspects of the program. The staff complained about Craig messing his pants everyday—it turned out nobody was remembering to put him on the toilet. The staff made no efforts to include Craig in activities with the other children; he spent most of the day aimlessly walking around with his lunch box.

I called a meeting with the director. I explained that Craig had autistic characteristics and tended to fixate on objects. I suggested they put the lunch box out of his reach and offer him the chance to participate in more beneficial activities.

Craig interacts with a friend at daycare.

I hoped this meeting would make things better, but things became worse. I walked into the center one day and, to my horror, found Craig restrained in a chair with a belt. A staff member told me she was "trying to teach him something."

I called another meeting and demanded they stop using restraints with my son. I told them Craig would sit still if he was involved in an interesting activity.

But the staff continued to restrain Craig. I called his case manager at the state mental retardation board. We met with the center director and her immediate superior. The center director and her boss kept referring to "Craig and the kids."

I explained that Craig *is* one of the kids. "You wouldn't strap a typical child to a chair, would you?" I asked.

I decided to go straight to the top. I called another meeting—this time with the program's regional director. I explained my reasons for choosing the program and told her how badly I wanted it to work. I reminded her that Craig had a legal right to participate.

Eventually, local director was fired; since then, the situation has improved. And to make sure it continues to be a good environment for Craig, his case manager makes frequent surprise visits.

—Colleen Nowotka
Toledo, Ohio

Readers talk about:

We invite you to the discussion in future issues of EXCEPTIONAL PARENT. In upcoming months, readers will be talking about:

- facilitated communication (May; deadline March 15, 1995)
- talking with a child about his or her disability (June; deadline April 1, 1995)
- helping a child make friends (July; deadline May 1, 1995)
- experiences with genetic counseling (August; deadline June 1, 1995)
- educational options—special schools or inclusion (September; deadline July 1, 1995)

Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).*

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Wet, But Happy

My five-year-old son, Ben, has multiple, severe disabilities as the result of a rare genetic disorder. He is very social and loves to be with other children. This year, for the first time, Ben is attending a regular daycare program—a district-operated after-school program for school-age children; Ben is the only child with a disability. I chose this program because it is the one his brother attends and because it is my intention that Ben be fully included for kindergarten next year at the neighborhood school where this program is housed.

The staff expressed some concern, but no actual resistance to including Ben. After two months, everyone seems pleasantly surprised at how easy the transition has been and how well Ben fits into the program. The staff loves him; he loves the program; and I am thrilled to see the other children treating him like just another kid.

The one huge wart on this otherwise pretty picture has been the district administrator to whom the program director reports. She has instructed the staff that they are not to assist Ben with toileting. Ben still wears diapers, stays dry for long periods of time, and almost never has a bowel movement in the afternoon, so this has not yet become a practical problem. It is inevitable, however, that Ben will someday have a bowel movement while at daycare. The administrator's solution is that a staff member will call me at work and I will stop whatever I am doing and come to change his diaper.

An even greater problem is that Ben is in the process of becoming toilet trained. He is not physically able to pull down his pants or to move from his wheelchair onto the toilet—for him, toilet training means learning to ask to use the toilet. We are pleased that he has started to communicate his need to use the bathroom. However, if and when he communicates that need at daycare, the staff have been instructed to tell him, "Sorry kid, you're on your own." My efforts to tell the administrator how devastating this could be to Ben's self-esteem has been met only with sympathy for my "situation."

Ben's next IEP meeting is coming up and I intend to include his participation in this program as part of his IEP. At that point, if the district administrator still refuses to accommodate his toileting needs, I intend to file a complaint with the Office of Civil Rights.

In the meantime, Ben is happy—albeit wet. The staff is doing a great job despite the constraints placed on them by their administration, and the other kids in the program are learning that kids with disabilities are more like them than different.

—Marcia C. Todhunter
San Francisco, California

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Circle # 90

Child Care and the ADA

by Rita D. Siegle

The Americans with Disabilities Act (ADA) is a powerful statement of civil rights for persons with disabilities. Title III of the ADA prohibits discrimination on the basis of a disability for many private businesses; this explicitly includes daycare centers. All child care programs, including family daycare homes, must comply with the ADA.

Defining discrimination

The ADA defines a person with a disability as someone:
- with a physical or mental impairment that substantially limits one or more of the major "life activities" (caring for oneself, performing manual tasks, walking, seeing, speaking, breathing, learning or working),
- with a history of such an impairment (for example, a child who had cancer but is now in remission), or
- regarded as having such an impairment (for example, a child with a cranio-facial condition who "looks different").

The ADA prohibits child care programs from discriminating against any child in one of the above categories. It also prohibits discrimination against a child who has a family member with a disability.

For more information...

These resources provide general information about the ADA. They can also answer questions and provide guidance with regard to specific situations or concerns.

The ADA Information Line
(800) 514-0301 (voice)
(800) 514-0383 (TTY)
Callers may access recorded information and order publications 24 hours a day. To speak with an ADA specialist from the US Department of Justice, call Monday–Friday, 10 a.m.–6 p.m. EST.

Child Care Law Center
(415) 495-5498 (voice)
Telephone intake hours are Tuesdays or Thursdays, noon–3 p.m. PST, or write to Child Care Law Center, 22 Second St., 5th Fl., San Francisco, CA 94105.

"Reasonable modifications"

The ADA requires child care providers to make "reasonable modifications" for equal access to program participation. These may include: revision of policies and procedures, removal of physical barriers, provision of adaptive equipment, curriculum adaptations and changes in staffing patterns and training.

Some exceptions

A provider is allowed to exclude a child with a disability if he poses a "direct threat" to himself or others, which cannot be overcome by reasonable modifications. But before a child can be excluded for this reason, the provider must document efforts made to include the child.

The provider may also exclude a child if accommodating the child:
- requires changes that fundamentally alter the nature of the program, and there are no reasonable alternatives.
- requires provision of equipment or services that would be an "undue burden" (significant difficulty or expense) on the provider, and there are no alternative accommodations.
- requires architectural changes that are not "readily achievable" (easily accomplished without significant difficulty or expense), and there are no readily achievable alternatives.

"Undue burden" and "readily achievable" can have different meanings depending on a program's resources. For example, a large chain of child care programs that typically provides transportation services may be able to buy a wheelchair lift for a van; for a family daycare home, this would create an "undue burden."

Denying care to a child under an allowable exception does not mean a provider may exclude others with the same disability. Each child's needs must be assessed individually.

Grey Areas

- **Cost:** Even if accommodating a child results in additional expenses, the facility may not charge his or her parents extra fees. However, these costs may be passed on to all participants in the program.
- **Disclosure:** Parents are not required to disclose a child's special needs. But if not disclosed, a provider cannot be expected to accommodate those needs.
- **Religious entities:** The ADA exempts programs operated by religious organizations *unless* they receive *any* type of federal funding.

Ian Keith (in stander) enjoys art class at Rainbow Station Child Development Center in Richmond, Virginia. Ian has cerebral palsy and is hard of hearing.

Rita D. Siegle, M.Ed., works at Dependent Care Management Group, a consulting company in San Antonio, Texas, where she supervises a child and elder care resource and referral program.

This article has been adapted with permission from CHILD CARE FOR ALL CHILDREN: A REFERRAL COUNSELOR'S GUIDE TO INCLUSIVE CARE. *(See* CHILD CARE RESOURCES *on page 35.) Funding for the book was provided by the Texas Employment Commission Work and Family Clearinghouse through a Dependent Care Block Grant. The book was written by Rita with support from Nancy Hard, president of Dependent Care Management Group and project manager of the Inclusive Child Care Project of Texas.*

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Child Care Resources

ADA-RELATED PUBLICATIONS

The ADA and Child Care Providers
Answers questions providers may have about ADA requirements. **Free.**
• Action for Better Child Care, United Cerebral Palsy of Greater Atlanta, 1776 Peachtree St NW, Ste 522 S, Atlanta, GA 30309, (404) 892-2252

All Kids Count
For caregivers and parents. Lists resources. 89 pp, **$12.50.**
• The Arc, PO Box 1047, Arlington, TX 76004-1047

Caring for Children with Special Needs: The ADA and Child Care
For child care providers. Addresses legal concerns. 40 pp, **$10.**
Child Care and the ADA: Highlights for Parents
For parents of children without disabilities. 16 pp, **$5.**
Child Care and the ADA: Highlights for Parents of Children with Disabilities
Overview of ADA requirements; actions to take if a program does not comply with ADA. 19 pp, **$5.**
• The Child Care Law Center, 22 Second St, 5th Fl, San Francisco, CA 94105, (415) 495-5498

Understanding the ADA: Information for Early Childhood Programs
For child care providers. **Free.**
• National Association for the Education of Young Children, Box ADA, 1509 16th St NW, Washington, DC 20036

GENERAL PUBLICATIONS

Caring for Children with HIV or AIDS in Child Care
For child care providers. Legal issues, practical concerns. 36 pp, **$10.**
• The Child Care Law Center, 22 Second St, 5th Fl, San Francisco, CA 94105, (415) 495-5498

Child Care for All Children: A Referral Counselor's Guide to Inclusive Care
Comprehensive guide for referral counselors. Shows how parents, providers and counselors can work together to make inclusion work. 80 pp, **$20.**
• Dependent Care Management Group, 130 Lewis St, San Antonio, TX 78212, (210) 225-0276

Child Care for Children with Special Needs
Helps parents assess how well child care providers address children's needs. Outlines key questions to ask. **Free to MN parents; $2 for others.**
• PACER, 4826 Chicago Ave S, Minneapolis, MN 55417, (612) 827-2966

A Great Place to Be Me: Selecting a Child Care Program When Your Child Has a Disability
Information guide for parents. 20 pp; **$7.50.**
• Child Care Plus, Rural Institute on Disabilities, The University of Montana, 52 N Corbin Hall, Missoula, MT 59812, (800) 235-4122

Including All of Us—An Early Childhood Curriculum About Disability
Guide to developing a classroom that is nonsexist, multicultural and accessible. Pub. 1964, 144 pp, **$10.95.**
• Gryphon House, 3706 Otis St, PO Box 275, Mt Rainier, MD 20712

Including Children with Special Needs in Early Childhood Programs
Research monograph. Practical tips. 230 pp, **$8.**
A Place For Me: Including Children with Special Needs in Early Care and Education Settings
General guide for providers. Addresses questions typically-developing children may have. 85 pp; **$4.50.**
• National Association for the Education of Young Children, 1509 16th St NW, Washington, DC 20036

In the Mainstream—From the Beginning?
Final report of a statewide (NY) study of child care for children with disabilities. Includes descriptions of programs and quotes from parents. **Free.**
• New York State Developmental Disabilities Planning Council, 155 Washington Ave, 2nd Fl, Albany, NY 12210, (800) 395-3372

Integrating Children with Special Needs into Pre-School Settings: A Resource HandBook
Extensive bibliography of resources. 87 pp, **$5.**
• Child Care Careers Institute Information Clearinghouse, 71 Summer St, 3rd Fl, Boston, MA 02110, (617) 338-6420

MITCH—Model of Interdisciplinary Training for Children with Handicaps
Series of 13 easy-to-read manuals covering all aspects of caring for children with disabilities in inclusive settings. 80–130 pp, **$5–7 each.**
• MITCH, c/o FDLRS/South, 5555 SW 93rd Ave, Miami, FL 33165, (305) 274-3501

More Alike Than Different: Including Children with Special Needs in School-Age Settings
Curriculum for a series of 12 workshops to train child care providers. Includes instructions and handouts. **Free.**
• New Jersey Department of Human Services, 222 S Warren St, CN 700, Trenton, NJ 08625, (609) 984-0879

Questions and Answers: Choosing Child Care for Children with Special Needs
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For child care providers. Lists resources for more information. 32 pp, **$3.**
• Community Coordinated Child Care, 225 Long Ave, Bldg 14, Hillside, NJ 07205

The SpecialLink Book: On the Road to Mainstream Child Care
Reference guide to inclusive child care in Canada and a record of the SpecialLink Symposium. 178 pp, **$18** *(US or Can.)*
• SpecialLink, 186 Prince St, Sydney, NS Canada B1P 5K5, (902) 562-1662

VIDEOTAPES

ABC's of Inclusive Child Care
Shows a variety of child care settings in which children with disabilities have been included; 14 min. **Free.**
• Texas Council for Developmental Disabilities, Attn: Lucy Walker, 4900 N Lamar Blvd, Austin, TX 78751-2399 (512) 483-4093

Just a Kid Like Me
Demonstrates three environments—a family daycare home, a child care center and a school-age program—integrating children with disabilities. 28 min., **$25 purchase; $15 rental.**
• Child Care and Family Services, 155 N Occidental Blvd, Los Angeles, CA 90026, (213) 427-2700

The Mainstream Is the Right Stream
Shows methods for including children with disabilities. One segment gives an overview; four segments show children with blindness, a medically-fragile condition, cerebral palsy and autism being included. Available in English or French. 60 min., **$40** *(US or Can.)*
• SpecialLink, 186 Prince St, Sydney, NS Canada B1P 5K5, (902) 562-1662
Same Time, Same Place
Shows children with different types of disabilities in three different child care settings. 15 min., **$18.**
• Continuing Education Administration Business Office, 1586 Stewart Ctr, Rm 110, Purdue University, W Lafayette, IN 47907-1586, (800) 359-2968

AUDIOTAPES

Action for Better Child Care Audio Newsletters
Quarterly audio newsletters offer information to providers on general child care and ADA questions. 7–14 min. each, **$2.**
• Action for Better Child Care, United Cerebral Palsy of Greater Atlanta, 1776 Peachtree St NW, Suite 522 S, Atlanta, GA 30309, (404) 892-2252

SpecialLink

Promoting a vision of inclusive child care in Canada

SpecialLink, Canada's National Child Care Mainstream Network, is a non-profit organization that grew out of 15 years of front-line work in an inclusive child care center that became a national model. The organization aims to increase the quantity and quality of inclusive child care in Canada and to bring children who are currently excluded into the mainstream. SpecialLink does research on successful, inclusive child care programs, develops resources for child care workers and parents and promotes changes in government policy.

SpecialLink works toward full inclusion in a milieu very different than the United States. In the U.S., laws mandate a "free, appropriate, public education" for children with disabilities (the Individuals with Disabilities Education Act) and outlaw discrimination on the basis of disability (the Americans with Disabilities Act). In Canada, however, the inclusion of children with disabilities in child care and educational settings is strictly voluntary. Nonetheless, hundreds of Canadian child care programs are finding ways to include all children.

Based on the best elements shared by these programs, SpecialLink has developed a vision of what Canadian child care will look like when it really includes *all* children. That vision presupposes a high-quality, affordable, accessible, comprehensive national child care system—it doesn't make sense to include a child with special needs in a poor-quality program; and it doesn't make sense to offer inclusive child care if the price, hours or location of that care make it inaccessible to families who need it. This vision implies many assumptions about funding, training, consultation, knowledge and commitment.

To promote the goal of inclusive child care, SpecialLink creates publications and videos (see "Child Care Resources," this page), and offers conferences and presentations spotlighting innovative, inclusive programs. U.S. readers who share the SpecialLink vision are invited to become "International members" of the network to receive the newsletter and other mailings (US $15/year). For more information, contact SpecialLink, 186 Prince St., Sydney, NS Canada B1P 5K5, (902) 562-1662.

—Sharon Hope Irwin, Director

ROLE MODELS

Irving Kenneth Zola

January 24, 1935 – December 1, 1994

Rereading Irv Zola's writings in EXCEPTIONAL PARENT, I again realized the magnitude of his loss—just as I had when sharing his memorial service at Brandeis University in mid-December with hundreds of others whose lives he had touched.

Below, we reprint an excerpt from an article by Irv, "A Story Difficult to Hear and Tell," originally published in EXCEPTIONAL PARENT in January 1979, a year before he joined our Editorial Advisory Board. Since this piece discusses serious topics, I want readers who did not have the privilege of knowing Irving Zola to know that he was a joyful person with a wonderful sense of humor. He was a loving husband, father and grandfather and a brilliant scholar—truly a role model.

Exactly 10 years ago—February 1985—we reported the death of Burton Blatt, another long-time member of our Editorial Advisory Board. Burt was another great leader, tireless advocate for human rights and personal friend. Knowing how Burt's influence has lived on helps me mourn now for Irv Zola.—S.D.K.

I am by professional training both a social observer and a psychological counselor. Yet, for more than two decades, I have succeeded in hiding a piece of myself from my own view. Given the obviousness of my physical disability, this has taken some doing.

Between the ages of 15 and 20, I suffered two major traumas—first polio and then, four years later, an automobile accident. Each resulted in a year's confinement and each was severely debilitating…

As a result of these "medical incidents," I wear a long leg brace on my right leg, a steel-reinforced back support and I use a cane. My children, when very young, described me as "walking funny." To the rest of the world, I limped. To me, all of it was just something that got in the way, another difficulty to be overcome. For 20 years, I devoted more psychological and physical energy to this task than I have ever realized. Overcoming is not the same as integrating. This is one of the bittersweet lessons…

For a long time, myself and many other "successful mainstream adapters" have not numbered among our close friends and acquaintances any handicapped people—a remarkable "alienation" from our disability.

Achievement syndrome

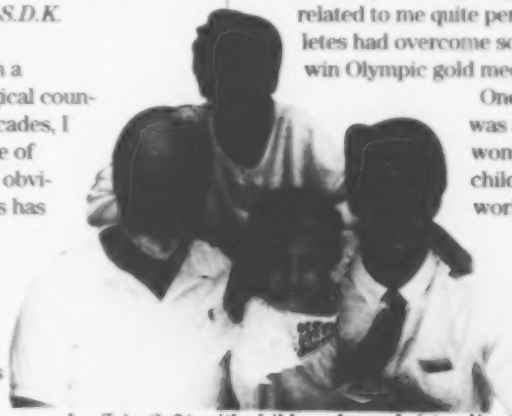
Written accounts about "successful" handicapped persons, as well as every "success" that I have met (including myself), almost always make this statement: "I never think of myself as handicapped." Yet the degree to which this is true may have made it virtually impossible to tell anyone what it is like to be disabled in a world of normal. In a real sense, we do not know. Thus, what the public learns from our example is decidedly limited…

So, too, with the other folk-heroes of disease—not the little people, not the millions, but the few who are so successful that they "pass." They are all so good that no one knows or has to be aware of their "handicap," and therein lies part of their glory…

I have come to realize how distorted and unrepresentative such "success" stories really are. The wish to disbelieve this is great. And we all—able-bodied and disabled—continually seduce ourselves into thinking otherwise. The media is particularly helpful in this task and a specific example sticks painfully in my mind.

I am a sports fan and, as such, an avid watcher of major events. The 1976 Olympics found me glued to my TV set and I was pleasantly surprised by a documentary which related to me quite personally… It told how six athletes had overcome some problem and gone on to win Olympic gold medals.

One story really grabbed me. It was about Wilma Rudolph, a woman who'd had polio as a child… Through exercise and hard work, she started to walk slowly with crutches. Then she abandoned them to begin to run. And there in the final frames she was springing down the track straining every muscle. With tears streaming down my face, I shouted, "Go on, Wilma! Do it! Do it!" And when she did, I collapsed, too—exhausted and exhilarated.



Irv Zola (left) with children Amanda(standing), Kyra (center) and Warren

But 90 minutes later I was furious. A basic message of the film had sunk in. In each case, the person overcame. But overcame what? Wilma's polio was not *my* polio! All my hard work could *never* have allowed me to win a running race, let alone compete in one.

My point is that in almost all the success stories that get to the public, there is a dual message. The first one is very important—just because we have polio, cancer or multiple sclerosis, or have limited use of our eyes, ears, mouth and limbs, our lives are not over. We can still learn, be happy, be lovers, spouses, parents—even achieve great deeds. It is the second message which I have recently begun to abhor. It states that if a Wilma Rudolph could overcome her handicap, so could and should all people

with disabilities. If we fail, it is *our* problem, *our* personality, *our* weakness…

Keeping a distance from the disability

…Achievement syndrome blinds not only the general public, but also the achievers. We are paid the greatest of compliments when someone tells us, "You know, I never think of you as handicapped." And we gladly accept it. We are asked, "How did you make it against such great odds?" And we answer the question. Yet, in both the being and the answering, we further distance ourselves from the problems of having a handicap. In a sense, they become both emotionally and cognitively inaccessible…

Let me illustrate with a personal example. I do a great deal of long-distance traveling and often find my flight leaving from a distant gate… Adjusting to this, I had ordinarily allowed myself an extra 20–30 minutes to get there. I regarded this as a minor inconvenience. And if, perchance, you had asked me then if I experienced any undue tiredness or avoidable soreness, I would have firmly and honestly answered, "No."

Irv (right) with daughter Kyra and grandson "Lucky."

In 1977, piqued that I should continue to inconvenience myself, I began to use a wheelchair for all such excursions. I thought the only surprise I would encounter would be the dubious glances of other passengers when after reaching my destination, I would rise unassisted and walk briskly away… But much more disconcerting, was that I now arrived significantly more energetic, more comfortable, freer from cramps and leg sores than in my previous decades of traveling. The conclusion was inevitable. I had *always* been tired, uncomfortable, cramped and sore after a long journey. But with no standard of comparison, I did not "experience" the tiredness and discomfort…

The very process of successful adaptation not only involves divesting ourselves of any identification with being handicapped, but also denying the uncomfortable features of that life. The denial of discomfort has made many success stories possible. But this process has a cost. One may accept and forget too much.

No Special World

There is no special world of the disabled person, and herein lies another major problem… Most minority groups grow up in some special subculture, and thus form a series of norms and expectations; the physically disabled are not similarly prepared. Born for the most part into normal families, we are socialized into that world… The very vocabulary we use to describe ourselves is borrowed from that society. We are *de*formed, *dis*eased, *dis*abled, *dis*ordered, *ab*normal, and most telling of all, *in*valid. Almost all of us share, deep within ourselves, the hoped-for miracle to reverse the process—a new drug or operation which will return us to a life of validity…

Whatever world the physically disabled and chronically ill inhabit, it is difficult enough to integrate into one's own experience, let alone communicate to others. There is a certain inevitable restraint, for what comes out seems like a litany of complaints. No one—at least not in my society—likes a complainer…

Chairs without arms to push myself up from; showers and toilets without handrails to maintain my balance; staircases without banisters to help hoist myself; buildings without ramps, making ascent exhausting, if not dangerous; every curbstone a precipice. With such trivia is my life plagued…

Sharing

With whom can I share the satisfaction that I did not trip, that my brace did not break, that I did not have difficulty with toilet facilities, that I made it by myself? When hospitalized with polio, I was tearful when I first defecated without the aid of a laxative. Even more exciting, after months of impotence, was my first erection.

My first steps in walking I could share, but not excessively, with my parents and friends. My bowel movements were at least acknowledged by the medical and nursing staff.

However, my sexual issues were kept achingly to myself. Even amongst my fellow residents, socialized as they were into the world of the normal, there was only limited access to any sharing… I gradually learned that no one, including myself, really wants to hear the mundane details of being sick or handicapped, neither the triumphs nor the hardships.

I am sure the specific details and hardships of having a handicap or chronic disease vary from person to person—but not the core problem. The story is inevitably difficult to both hear and tell… As such, the only defense, the only way to live, is to deny it. But then it becomes socially invisible to all. We—both those with physical disabilities and those without—are sadly left deprived of the very knowledge, skill, resources and motivation necessary to promote change.

IRVING KENNETH ZOLA SCHOLARSHIP FUND

As a founding member of the Society for Disability Studies and a conceptual architect of the field, Irv played a unique role in weaving together a community of scholars. He was personally involved in nurturing the work and lives of thousands of colleagues, students and advocates. We will miss his thoughtfulness and energy, his warmth and humor, and his courage and caring. Irv embodied what so many of us seek—the combination of intellectual insight and a life committed to humane values and social justice.

We have created the Irving Kenneth Zola Scholarship Fund to support the professional development of graduate students in disability studies.

—Richard K. Scotch, President, Society for Disability Studies

Contributions may be made to "Irving Kenneth Zola Memorial Fund" and sent to Fred Hafferty, Treasurer, Society for Disability Studies, 3109 E. Superior St., Duluth, MN 55812.

Proper Seating and Positioning

To participate in the everyday activities of life while using their maximum abilities, children with disabilities must be seated in a comfortable position. Proper seating and positioning allows children to use their bodies and minds to the best of their abilities without worrying about balancing and personal safety.

"A seating system is the center of all other activities," says Elaine Trefler, M.Ed., OTR, an assistant professor in the School of Health and Rehabilitation Sciences at the University of Pittsburgh and expert on seating and positioning. "If a child is well seated and comfortable, the child will be able to participate at his or her optimum."

When to start

Although premature babies have been fitted for positioning equipment, parents are likely to begin the process when their child is about six months old because of the increased need for and use of car seats, highchairs and strollers. This is also about the time when a diagnosis is clear and the child may start to fall behind on motor skill development.

The most important step for ensuring a child is fitted with a proper seating and positioning system is a thorough evaluation and prescription by a qualified team. The team should include physical or occupational therapists, a physician specializing in rehabilitation medicine or orthopedics, a rehabilitation technology supplier and parents.

Other members of the team may include school therapists and classroom teachers if the child is in school, and a rehabilitation engineer if the child has severe disabilities and needs a custom-designed system.

KISS (Keep It Simple Simulation) Simulator by Pin Dot Products, Northbrook, IL.

Finding the right team

Not every therapist or health care provider is properly trained to evaluate and prescribe the proper components for seating and positioning.

There is no formal training or testing to accredit health care providers who specialize in seating and positioning. RESNA, an organization of rehabilitation professionals, is developing guidelines that may be used to certify specialists in this area.

Parents need to ask about their team's experience—What seating and positioning equipment have they worked with, how many years have they worked in the seating and positioning field, and what type of conferences and training programs do they attend?

Although some professionals may be offended when asked about their expertise, these questions are important. "Why do we feel comfortable asking the qualifications of the TV repair man but not the people looking after our health?" asks Trefler, adding, "If the professional is not willing to share—or if they become offended—the parent might need to go elsewhere."

A qualified team will make sure the parents are involved with the evaluation and the choice of seating and positioning equipment. Trefler advises parents to ask themselves, "Are they (the parents) just going to a clinic and being told what's right or are they truly being included as one of the team members?"

A qualified evaluation team should:

- Ask parents about the child's lifestyle, his or her environment at home and school and overall community involvement. Ideally, the team would be able to observe the child in these different environments.
- Use techniques to simulate different positioning options. This can be done with a seating simulator, a device that simulates different systems by changing seat and back angles and positions. Simulators help determine the correct size of the system and its different accessories.

If a simulator is not available, the team should use various mobility bases, such as wheelchairs, and positioning components, which may include different seats and backs, to simulate different options.

- Use a pressure mapping system to help avoid pressure sores, known technically as *decubitis ulcers*. Children who are unable to shift weight independently in a system or lack sensation in parts of their body are prone to sores. Sores can lead to dangerous infections, discomfort and costly treatment. Many cushions have been developed for pressure relief.
- Consider the child's use of technology, such as computers, augmentative communication devices or any other devices that improve the child's quality of life. The child should be positioned in order to take full advantage of these technologies.
- When possible, ask the child what he or she is comfortable with. This includes questions about the different angles and equipment arrangements and color and fabric preferences.
- Help parents find funding.

Standers and bed positioners

Parents can also want to ask about therapeutic positioning devices such as standers or bed positioners. Again, parents will want to make sure they are involved with the evaluation and selection process and that the team is qualified to evaluate their child.

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What to buy

There is no one formula that can be applied to every child to determine proper seating and positioning. Because of the ever-growing commercial availability of different equipment, customized systems (those created specifically for a particular child) may not be necessary. Instead, parents may be able to purchase different components that could be used together to create a suitable system recommended by the team.

The Chameleon, a three-in-one infant stander, by J.A. Preston, Jackson, MI.

When possible, a child can try out the equipment before a purchase is made. Although customized systems usually cannot be tried out before purchase, dealers can loan parents different pieces of equipment for the child to try at home overnight.

Stand back and look

Most children will have to be reevaluated every two to five years for a new seating system. Cushions in the systems may need to be replaced more often because of wear and tear and the loss of pressure-relieving qualities. If the total system design is not being changed, parents can buy new cushions directly from dealers without consulting the evaluation team.

The system may need to be changed if the child:

- Is unable to maneuver objects as easily as in the past.
- Looks uncomfortable or complains of discomfort.
- Has gained substantial weight.

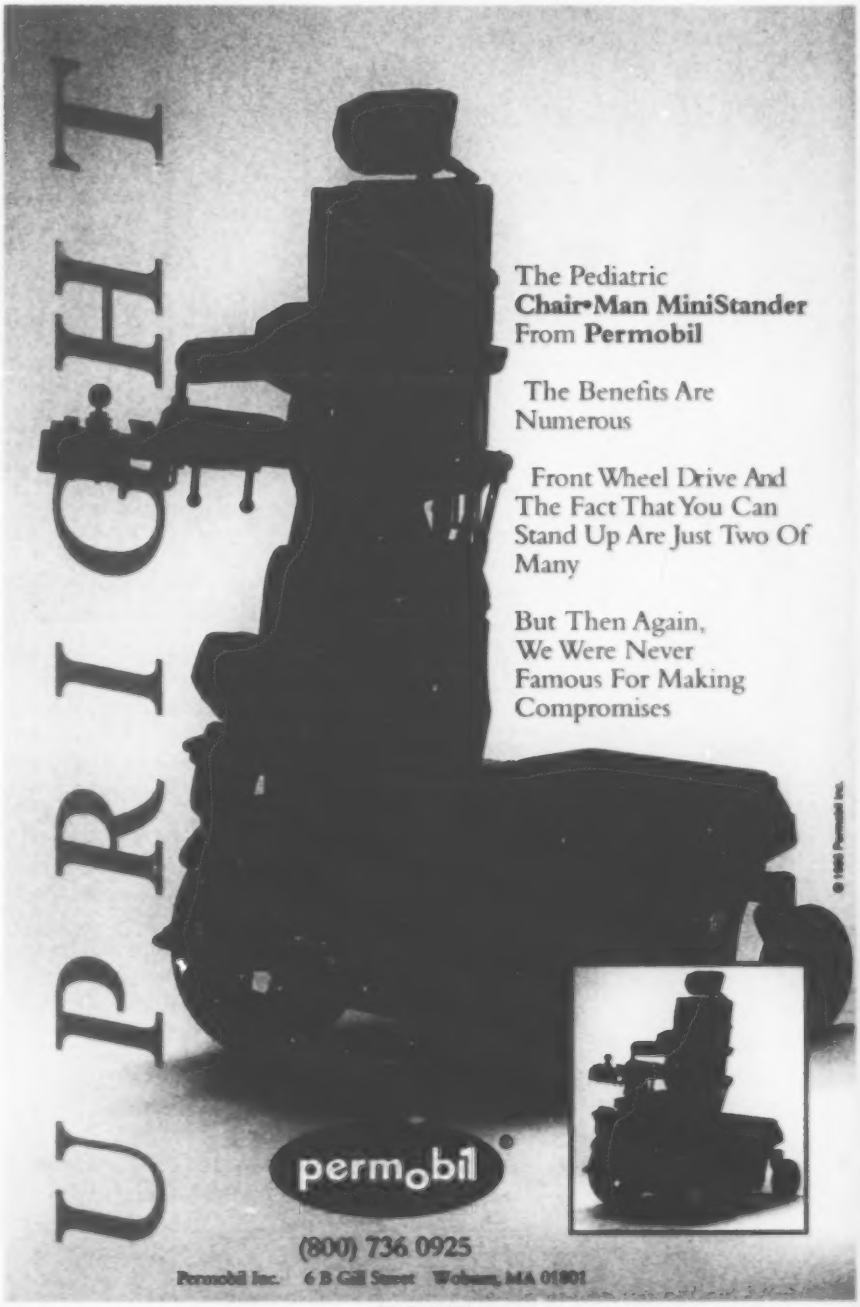
"If there's anything we can teach therapists and parents, it is to stand back and look," Trefler says. "Look at the child and how she is functioning. They'll spot problems."

Fitting the bill

Seating and positioning equipment costs range from hundreds to thousands of dollars depending on the child's needs. Most health insurance companies or Medicaid will pay some—if not most—of the cost. Insurers are likely to pay if the evaluation team justifies the cost. If parents need additional funding after insurance benefits are used, they can ask equipment dealers and/or contact local service organizations.

—Marc S. Malkin

Thanks to Elaine Trefler, M.Ed., OTR, FAOTA (Fellow of the American Occupational Therapy Association) for her help in compiling this article.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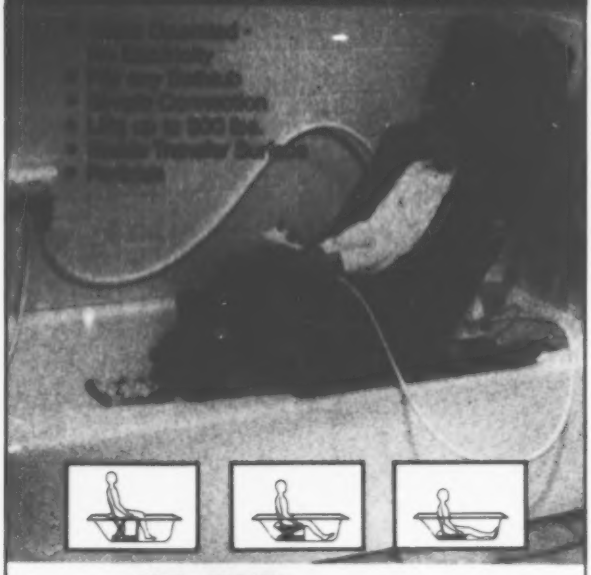

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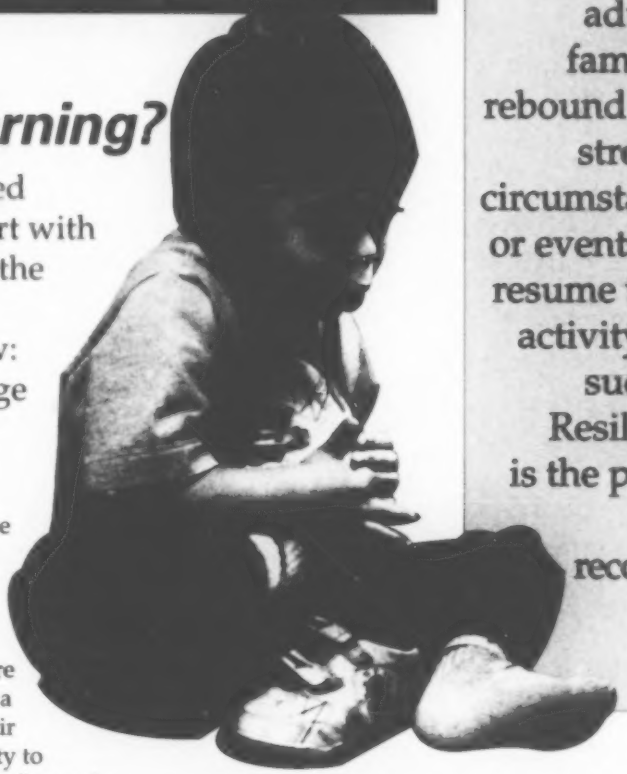
CENTER FOR CHILDREN WITH CHRONIC ILLNESS AND DISABILITY

Children's Health Notes

Project Resilience:
What Are We Learning?

After two interviews conducted approximately 18 months apart with the 120 families that make up the Minnesota infant cohort, the research team wanted to know: Does family functioning change following the diagnosis of a child's chronic condition?



It turns out that most families continue to do well within two years of diagnosis. Some 76 percent of the families report there is no change in family functioning.

However, a significant number of families say they struggle with the effects of providing care for their child with a disability. At the time of the second interview, 21 percent of families report they are experiencing a change in their family's ability to function. This change in their ability to successfully accomplish tasks and roles and with their success in communicating with one another can also be seen in the way both the father and the mother interact with their child. Parents may be a little distant, engaging less in playful communication.

Mothers in this group report that characteristics of the chronic condition contribute to the stress in their lives. This is particularly true when their children have cognitive, respiratory, sensory and mobility disorders. Fathers report that marital adjustment, characteristics of the chronic condition, and the father's depression contribute to a decline in the way the family functions.

The analysis of this data show child behavior problems are not determined by the chronic condition only. Mentally and physically healthy parents and the healthy functioning of families are "protective" factors that enhance resilience in the first 18 months after diagnosis. These changes might indicate an overall change in functioning, but that conclusion requires further study.

DEFINITION

Resilience
The tendency for a child, adult or family to rebound from stressful circumstances or events and resume usual activity and success. Resilience is the power of recovery.

INSIDE

The Center for Children with Chronic Illness and Disability is learning a great deal about children with chronic illness and disabilities, their families, and the political, health care, and policy environments that affect their care. To reach as many families as we can, we join with *Exceptional Parent* to publish *Children's Health Notes* to define the environment, raise questions, identify strategies, or provide clarification of issues that are critical to providing care for children with special needs and their families.

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Children's Health Notes

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What Kinds of Activities, Behavior & Relationships Promote Resilience in Families?

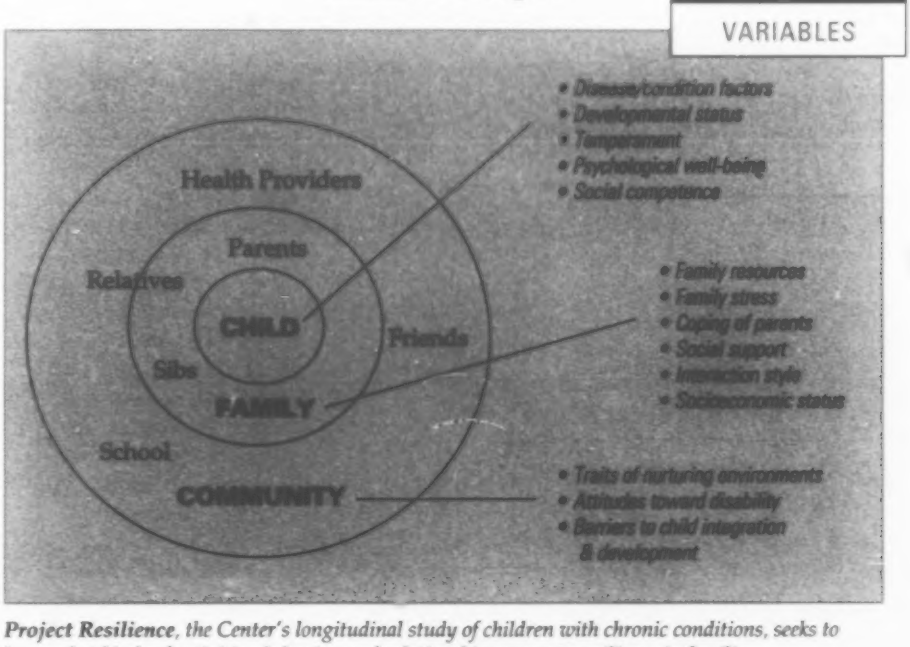
More and more, we find examples of children and youth who seem to thrive despite what appear to be overwhelming odds.

And it's not just those like Marlee Matlin who becomes an Academy Award-winning actress despite being deaf, or Judy Heumann who becomes a teacher and then Assistant Secretary of the Office of Special Education & Rehabilitative Services (OSERS) despite her quadriplegia and need to use a wheelchair.

- It's the 10-year-old who, after several amputations, writes the humorous short story, "The Leg with an Ego."
- It's the plucky 8-year-old with cerebral palsy who goes to school with your son or daughter and is getting A's!

What makes these children and youth able to accomplish the "developmental tasks of childhood," to allow them to "fit in" and thrive?

Most physicians and therapists, teachers and social workers spend their time diagnosing and treating what's wrong with a child who has a chronic illness or disability. Rather than dwell on the weaknesses, we wanted to know "What are the strengths of children and families?" So we began asking these questions more than five years ago as part of ***Project Resilience***, a longitudinal study of factors predicting competence in children with chronic illness. This study is designed to investigate, over time, the risk and protective factors associated with optimal psychological, behavioral, and social functioning and development of the child with chronic conditions and his or her family. Included here is a preview of some of the earliest findings.



***Project Resilience**, the Center's longitudinal study of children with chronic conditions, seeks to learn what kinds of activities, behavior, and relationships promote resilience in families.*

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Project Resilience involves 330 children with chronic conditions and their families. By design, the children who are participating are affected with a range of conditions—from heart disease to juvenile arthritis, epilepsy to blindness. That's because we, like others, believe that the impact of chronic illness and disabilities on a child's development is more similar across conditions and disabilities than different. Families respond to questionnaires, and trained interviewers ask standardized questions, conduct and record interviews, and videotape interactions between children and parents. What we learn could influence program and policy development.

Background

Just What Is A Longitudinal Study?

The purpose of longitudinal research is to study the lives of children (or any group of people) over time—a long time—*sometimes a generation*. Researchers at **C3ID** propose to study the growth and development of children, in some cases, from the diagnosis of a disability within the first year of life through to adulthood.

C3ID isn't the first to conduct a longitudinal study of children. Many of our assumptions come from a 30-year study of the roots of resiliency and the sources of strength and vulnerability found in a multiracial group of children who grew up in poverty on the Hawaiian Island of Kauai. These researchers, Emmy E. Werner and Ruth S. Smith, show that a balance between risk factors, stressful life events, and protective factors within the child and the environment accounts for the range of adaptive (and maladaptive) outcomes in human development.

Approximately half of the families **C3ID** are studying were recruited within the first 18 months of their child's diagnosis. With this infant cohort, research staff are examining the course of development from the first year of life. The other participants were recruited when the children were between 8 and 10 years of age. These preadolescents will help us understand the added challenges of adolescence. About half of all participants live in the Twin City area; the other half live in and around Seattle, Washington. Our goal is to understand what distinguishes the child with a chronic illness or disability who grows up to work well, play well, love well and expect good things.

RESEARCHERS

Robert William Blum, M.D., Ph.D., Joän Patterson, Ph.D., Randy Stinchfield, Ph.D., and Ann Garwick, Ph.D., were co-presenters at a symposium, "Understanding Resilience in Families of Children with Chronic Conditions," during the Annual Meeting of the National Council on Family Relations held in Minneapolis, MN, on Nov. 8–13, 1994. The information presented here is based on that presentation. Blum, Stinchfield and Garwick are members of the Division of General Pediatrics & Adolescent Health in the University of Minnesota Medical School, and Patterson is in the Department of Maternal & Child Health, School of Public Health, at the University of Minnesota. Their research is supported, in part, by the National Institute on Disability and Rehabilitation Grant #H133B40019.

FOR MORE INFO

If you want to read more about *Project Resilience*, you can read the following journal articles:

"Vulnerability and Resilience of Children and Their Families," published in *Pediatric Annals*, Vol. 20, No. 9, Sept. 1991.

"Levels of Meaning in Family Stress Theory," published in *Family Process*, Vol. 33, Sept. 1994.

When Physicians First Talk to Parents:

Heading Families in the Right Direction

Families vividly remember the time when they learned about their child's condition.

That's why C3ID interviewers tape record families' responses to these questions:

- Would you go back to the time when you first learned about your child's condition and talk about what happened?
- What were you told?
- Who told you?
- What were your reactions?

Drawing on the responses of families with children diagnosed with Down syndrome, families with children diagnosed with congenital heart disease, and families with children diagnosed with both, researcher Ann Garwick discovered most talk about the sensitivity of the health care professional and the quality of information that person provides.

Families learning to accept their child with Down syndrome worry about the future and talk a great deal about the future when their child will be a young adult.

However, parents whose children are born with life-threatening heart disease recall the fear and anxiety about the immediate outcomes. They describe coping one day at a time with little vision of the distant future.

Interestingly, when a child was born both with Down syndrome and congenital heart disease, the issues overlap. Sometimes what is first on their minds depends on the particular issue with which they are dealing.

This qualitative study concludes that how parents are informed that their child has a chronic illness or disability affects how the family functions in the first 18 months of a child's life. Parents' responses indicate that health providers need to really evaluate how they talk to families.

Families had negative reactions to first learning of a child's diagnosis in the presence of strangers or by telephone. Many indicated that they had received outdated or inadequate information.

Families had positive reactions to health care professionals who were supportive and sensitive to their feelings, kept them informed about their child's condition, and focused on their child as a whole person.

Before talking to families, the professional should consider an individual family's background, including: pregnancy, labor and delivery experience, expectations for a healthy child, condition of the child and parent(s), beliefs about chronic illness and disability, knowledge and experience with the child's type of condition, awareness of media portrayals of the child's condition, and the relationship between the family and physician.

RESULTS

Breaking the news of a child's disability or chronic condition is a critical event for families. Ann Garwick suggests that health professionals P*A*C*E the News:

***Plan** the setting.

***Assess** family's background.

***Choose** strategies that best fit the family and their situation.

***Evaluate** their understanding of the news.

The **Center for Children with Chronic Illness and Disability** was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.

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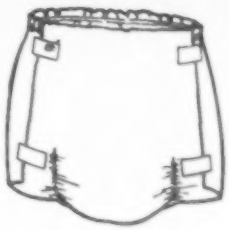

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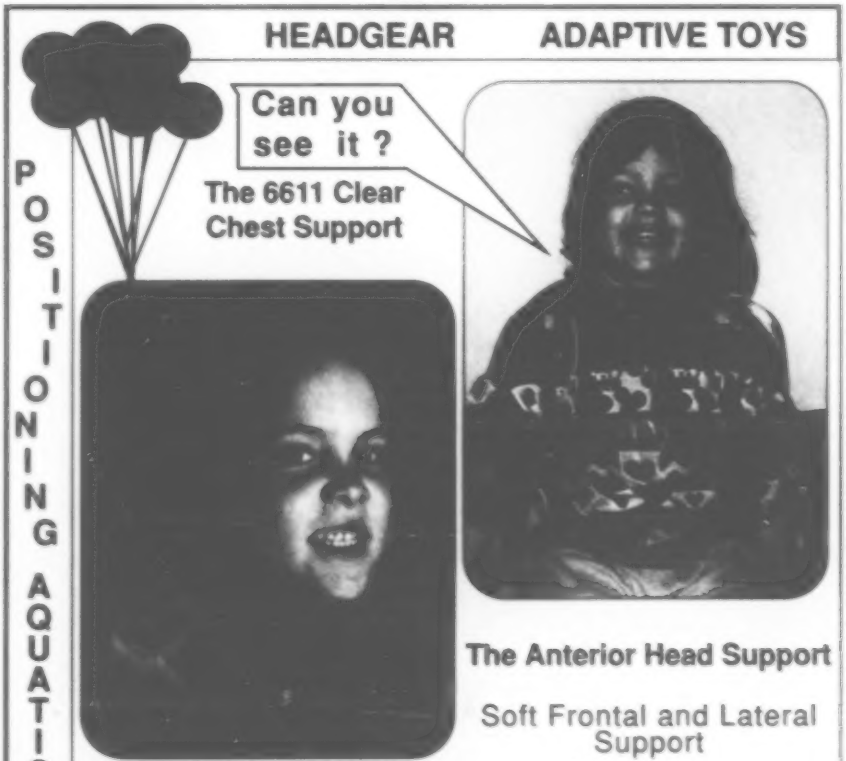

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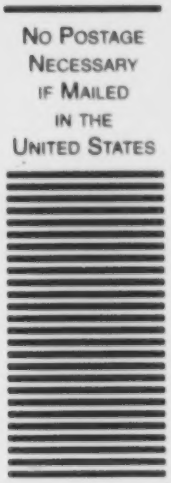

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New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

New York

Arcola Mobility
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Carlstadt, NJ 07072
(201) 507-8500/(800) ARCOLA-1
New-Used-Trade-Lease-Buy. Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

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Pennsylvania

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors; drop floors; custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

LIVING AND LEARNING IN THE COMMUNITY

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EVERGREEN CENTER
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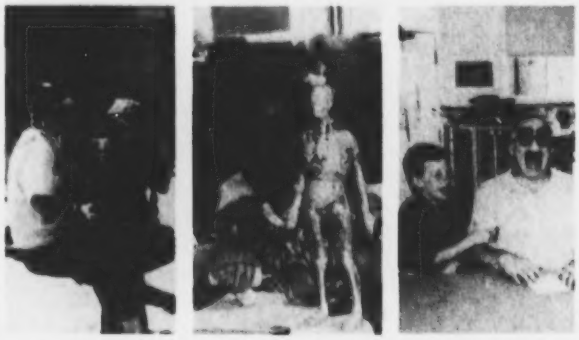
1-508-478-5597

Circle # 106

COTTING SCHOOL

"Congratulations. You've Just Found a Place for Your Child to Thrive."



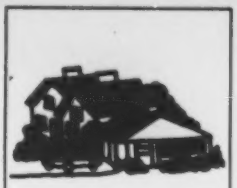
Cotting School is a 766-approved day school in Lexington, Mass. serving children and young adults, ages 3-22, with a variety of physical, medical, and learning challenges.

Cotting's program features: physical, occupational and communication therapies • art, music and drama classes • prevocational and off-campus internship programs • basketball and track & field teams--and more--all under one roof! We give your child every opportunity to succeed.

At Cotting School, your child will be nurtured and stimulated, not set apart.

For more information or a tour, call Bob Driscoll, Director of Admissions, at (617) 862-7323.

Circle # 181



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(617) 893-6000

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For registration brochure, poster session guidelines, exhibit application or scholarship information, contact: Parent Care, Inc., 9041 Colgate Street, Indianapolis, IN 46268-1210; Phone & FAX (317) 872-9913

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NEW PRODUCTS

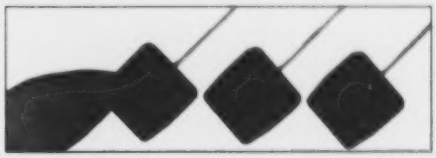
BEASY II

This no-lift transfer system helps parents lift a child while reducing the risk of back injuries. It also makes it easier for children to transfer by themselves. This shorter version of the BeasyTrans accommodates space restrictions in home settings, especially in the bathroom. The circular seat rotates 360 degrees and slides laterally.

Beatrice M. Brantman, Inc., Lake Forest, IL

Circle # 195

STEP ON IT!



Keyboard control pedals offer easier access and greater productivity for amputees, people with limited hand abilities or blind touch typists. Three electronic foot switches are programmed by the user to assign and reassign any three keyboard keys to floor operation. Compatible with any IBM PC or clone, 286 and higher.

BILBO Innovations, Inc., Madison, WI

Circle # 196

ALADDIN

This personal reader is affordable for parents and easy for a child to use. Magnification is selected by the user. The reading table allows viewing of heavy reading material—including dictionaries—and is designed to fit in the home, classroom or office. Has a five-year warranty and a 30-day money-back guarantee.

TeleSensory Corporation, Mountain View, CA

Circle # 197

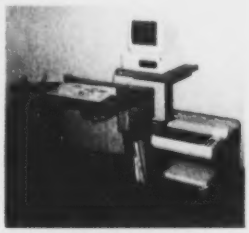
STEP 'N GO STAND UP CYCLE

For recreation or physical therapy, this stand-up cycle may be the answer for children with head injuries, cerebral palsy or limited lower-limb range of motion. Little balance is required for riding, mounting or stopping. A treadle motion allows short, large or uneven steps to power the cycle. The "backwards triangle" design creates a stable base.

Treadle Power, Inc., Charlotte, VT

Circle # 198

ASSISTIVE DEVICE CLASSROOM DESK



Portable and height-adjustable, this desk is specifically designed for wheelchair users. The top's inset tilts and stops at various angles for easier viewing of textbooks and papers. Options include a book box, which can be attached to either side of the frame, and a full computer work station with a pivoting monitor stand.

EBM Corporation, Gladwin, MI

Circle # 199

CHILD GUARDIAN PLUS

This child locating system and home care paging alarm also acts as a personal or property alarm. The parent carries an electronic transmitter while the child wears the receiver alarm around the waist in a fanny pack. For home care use, the child uses the transmitter to activate the receiver alarm when assistance is needed.

Direkt Inc., Springfield, VA

Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 products for persons of all ages who have a physical, sensory or cognitive disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers in each listing are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 46) to get more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TTY, (301) 588-9284, V/TTY or (301) 587-1967, FAX.

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Circle # 70

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Circle # 110

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1-800-582-8732

Circle # 39

197

ASK THE DOCTOR

by David Hirsch, M.D.

Toilet Training

Q We have a seven-year-old daughter who is blind due to retinopathy of prematurity and has an amputation of her right leg above the knee for which she wears an artificial limb. She has mild cerebral palsy and is unable to sit unsupported. She often gets constipated.

We are trying to toilet train her but we are having problems because we have to remove her prosthesis to put her on the toilet. This causes her to become even more unbalanced. We think that toilet training is very important. Do you have any suggestions?

A I agree that toilet training is important for your daughter, not only for purposes of hygiene but also for her self-esteem. However, it is important not to toilet train her before she is ready. That could delay the process and even make her constipation problem worse. However, if she shows the proper interest in toilet training, you can try it.

First, you need to set up a mechanism so your daughter can sit on the toilet without losing her balance. This is essential for any child who is being toilet trained. You may want to have something she can hold onto with her hands.

If she is still small enough, you may be able to use a toilet seat or a potty chair, which is less intimidating. Take her to the toilet any time she asks to go. In addition, try taking her to the toilet after meals or at a time of day when she typically has a bowel movement.

Constipation will make toilet training more difficult. Try to increase her liquids in the form of natural juices and water. Unless she is on a special diet, you can increase the amount of fiber in her diet by increasing fruits and vegetables and decreasing the more constipating foods such as dairy products.

Clearly, you have come a long way with your daughter. Be patient, and toilet training will be another obstacle she will overcome.

Ask the Doctor is a regular department of EXCEPTIONAL PARENT *in which questions are answered by David Hirsch, M.D., a pediatrician and member of the Editorial Advisory Board of* EXCEPTIONAL PARENT. *Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

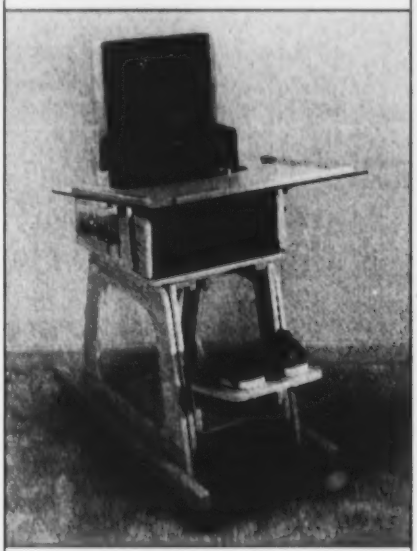
Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch mentions specific products or medications, he is illustrating his suggestions; he is not endorsing any specific products.

To submit a question, write or fax: Ask the Doctor, EXCEPTIONAL PARENT, *209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8742.*

The *New* LeisTech Positioning Chair!

Tired of the institutional looking positioning chair?

Take a look at this finely crafted piece of furniture.



The LeisTech chair correctly and comfortably positions the involved child for both classroom and home activities. Allows for years of growth and is easy to adjust. Available with a tilt in space option, and custom modifications to meet the needs of each child.

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Circle # 2

by Richard Epstein

SSI Rejections and Appeals

Q Our 12-year-old son is blind and mentally retarded. He also has cerebral palsy and hydrocephalus. Costs for his care are astronomical.

Several years ago, I applied for SSI for him because the level of his disabilities make him eligible for the benefits. After several interviews and countless forms, he was ruled ineligible because our income was too high. While our income seems high, once you start subtracting the cost of all my son's special needs, very little remains for the rest of the family.

I accepted the ruling. Since then, I have read that appeals are almost always successful. Is that true? Do you think that our family would have a chance of winning an appeal now?

B.F., Virginia

A This problem occurs frequently. It is frustrating for families with average or above-average incomes. SSI and the Medicaid health insurance benefits that generally accompany it were designed to meet the needs of people with limited incomes who have severe disabilities.

Although a family with average or above-average income may not have enough money to meet all of their child's special needs, family income may make the child with a disability ineligible for SSI or Medicaid.

Exceptions to income rules

There seem to be two exceptions to the eligibility rules. First, there is a special provision in the regulations for Medicare—rather than Medicaid—coverage for a child with kidney failure, even when a family's income exceeds the general Medicaid limits.

Second, there is a special waiver in the Medicaid regulations that provides for Medicaid coverage when a child with a disability is hospitalized and where at-home treatment would be appropriate and is less expensive than hospital-based treatment. In some states, this special waiver may apply even when the family's income is higher than the usual Medicaid guidelines. Aside from those exceptions, a family must meet eligibility rules to qualify for SSI or Medicaid. However, the rules can be rather complicated. And since eligibility rules differ from state to state, the situation is more complex than for other government programs.

In addition, eligibility rules in regard to income are different for SSI and Medicaid in many states. Several states, for example, have special rules that allow a family to deduct the cost of some medical expenses for a child with a disability in calculating total family income. Those rules, however, generally apply only to Medicaid eligibility, not to SSI.

I think that rejection of an SSI/Medicaid application should almost always be appealed, at least to the first level. The general rule is that an appeal should be filed within 60 days of a rejection. However, it's never too late to consider filing an appeal or a new application.

There are four different levels of appeals; they usually follow a specific order. The first level involves a request that another person within the local Social Security office review the application. If that does not result in a satisfactory decision, the second level involves a hearing before an administrative law judge.

The third level involves a review by the Social Security Administration's Office of Hearings and Appeals. And the fourth level involves filing a lawsuit in federal district court.

Appeals often result in a decision to grant SSI and/or Medicaid benefits, but there is no guarantee. However, the appeals process is fairly simple. Usually, you do not need an attorney, except at the federal court level.

The Arc, a national organization on mental retardation, offers free information on SSI and SSI appeals. Contact The Arc, 500 E. Border St., S-300, Arlington, TX 76010, (817) 261-6003 (voice), (817) 277-0553 (TTY). Ask for *Social Security and SSI Benefits For Children With Disabilities* and *Appealing a Social Security Disability Benefits Decision.* Send a self-addressed, stamped envelope.

The Social Security Administration also has two free booklets available on SSI benefits for children with disabilities. Copies may be available at your local Social Security Administration office. Or call (800) 772-1213 (voice); (800) 325-0778 (TTY).

You can get advice on appeals from your local legal services office. Contact the National Legal Aid and Defense Association, 1625 K St., NW, Ste. 800, Washington, DC 20006, (202) 452-0620 (voice) for the nearest office. Local Protection and Advocacy offices may be helpful, too. Call the local bar association for the nearest office.

Richard Epstein answers readers' questions about health insurance. Send questions to EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. Fax questions to (617) 730-8742.

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. To ensure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.

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Networking

Information from The National Parent Network on Disabilities

The National Parent Network on Disabilities Board of Directors

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Patricia McGill Smith
Executive Director

DON'T FORGET

Mark your calendars! NPND's next Annual Meeting will be held in Washington, Sept. 30–Oct. 2, 1995. Contact NPND for more information.

Thanks

NPND wishes to acknowledge and thank American Airlines and the National Association of Medical Equipment Suppliers for generously supporting our 1994 Annual Meeting and Reception.

IDEA at Crossroads in New Congress

As *Exceptional Parent* went to press, the 104th Congress had been in session for two weeks. Although the first 100 days of this session are dedicated to passing the major components of the Republican's "Contract with America," the Individuals with Disabilities Education Act (IDEA) is also scheduled for reauthorization during this session.

It appears that IDEA will be attacked in a variety of ways during the reauthorization process. This *Networking* is devoted to providing information for parents and professionals to respond quickly from an informed point of view.

Included are summaries of potential attacks on IDEA, along with positions of the National Parent Network on Disabilities (NPND). For a full understanding of these issues, NPND encourages family members and professionals to join NPND's Family Action Network (FAN). FAN will keep you up to date with developments in Washington.

Megan Donnelly plays with Miss America 1995, Heather Whitestone, and NPND executive director Patricia McGill Smith at the Herald Center Toys "R" Us store in New York City during the unveiling of the second edition of the TOY GUIDE FOR DIFFERENTLY-ABLED KIDS.

HERITAGE FOUNDATION RECOMMENDS REPEAL

The Heritage Foundation, a conservative Washington think tank, has recommended the repeal of 24 laws as part of a briefing for new members of Congress. IDEA was one of these laws.

• **NPND Position:** This challenge to IDEA has the greatest ramifications. While Part B of IDEA (all procedural safeguards regarding access to a free, appropriate education) is permanently authorized and does not face the challenges of reauthorization, it *can* be repealed. It is impossible to estimate how real the threat of repeal is at this time. It is significant, however, that the repeal has even been mentioned to new members of Congress who have not participated in previous discussions of this legislation.

UNFUNDED MANDATES

Senate Bill #1 (S1), principally sponsored by Republican Sen. Dirk Kempthorne of Idaho, is a bill which would limit Congress from imposing mandates on states without authorizing federal funds to help implement the mandates. S1 and its companion bill in the House of Representatives are racing towards passage. It appears that both IDEA and the Americans with Disabilities Act (ADA) will be exempt from this legislation, although there has been no written assurance of this from the many co-sponsors of these bills.

• **NPND Position:** NPND remains concerned because some of the criticisms of IDEA and the ADA have categorized these laws as unfunded mandates. As defined by S1, it appears that these laws are not unfunded mandates. NPND opposes any amendments to the legislation that would deem IDEA and the ADA unfunded mandates.

APPROPRIATIONS

Key members of the new House leadership have announced that the budget resolution will be the "transformational" document of this Congress. Congress can effectively abolish programs by failing to fund programs. Accordingly, programs do not have to be repealed, just not appropriated. Given the massive amount of cuts needed to balance the budget, it seems likely that the programs we care about—like SSI (Supplemental Security Income), IDEA, Medicaid and others—will suffer significant cuts.

• **NPND Position:** The budget offers many opportunities for cutting. No programs should automatically be taken off the table. All waste should be cut. In particular, defense spending should be reduced (along with many other programs) and not increased as it is now proposed.

These are just a few of the pressing concerns that face us in the current Congress. Everything is on a fast track! Things seem to change hourly. We must be more vigilant than ever.

In the words of Justin Dart, "We are now in the Valley Forge of our movement." We must remain unified! We must act to defend the rights of people with disabilities and the programs that empower us all.

200

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equipment shop

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Circle # 123

Life Planning Should Be A Team Effort

Every month, Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidance to hundreds of families with a son or daughter who is disabled. Our national network of attorneys and estate planners helps to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private and government benefits. EPPD provides FREE initial interviews to determine needs and FREE group seminars for parents. EPPD is not a guardianship or master trust, but assists parents in locating services necessary to provide a secure future for their loved one. Call today to receive a FREE brochure and the location of your nearest EPPD representative.

Richard W. Fee
Executive Director
National Office
1200 Corporate Drive / Suite 330
Birmingham, Alabama 35242

800-448-1071

ESTATE PLANNING FOR PERSONS WITH DISABILITIES

A Division of Protective Life Insurance Company

Circle # 31

Family Action Network to Save IDEA

The Family Action Network (FAN) to Save IDEA is NPND's special project to ensure that children with disabilities maintain their federal right to a free, appropriate public education.

Why FAN now?

Some members of the new Congress are seriously considering declaring IDEA an "unfunded mandate." Additionally, the Heritage Foundation, a conservative think tank, has called for the repeal of IDEA. If IDEA is repealed, children with disabilities will only have the rights granted by their states.

Part H of IDEA

If IDEA becomes defined as an unfunded mandate, children may lose services through Part H, a 1986 amendment to IDEA that does not require states to provide early intervention to children from birth to age three, but offers federal dollars to states interested in serving this age group. If IDEA is nullified, children will receive only the services each state decides to provide.

Won't the courts protect my child?

If IDEA is repealed, the last 20 years of court decisions will be meaningless. There will no longer be a federal law on which to back court decisions. NPND worries that if the federal law is nullified, states will also decrease—or even eliminate—services.

Why does NPND think IDEA may be repealed?

Although they have not said it outright, many members of the new Congress have indicated that IDEA will be seriously weakened, if not done away with altogether. Members of Congress are being urged to repeal IDEA by our opponents. Coupled with the movement to declare IDEA an unfunded mandate, it is distinctly possible that IDEA will not survive the 104th Congress.

Everyone can help

You can help save IDEA by joining FAN. FAN members will receive quarterly newsletters with updates on how IDEA is faring in Congress. Alerts of timely information and requests to take action to help save IDEA will be sent when necessary.

Professionals welcome

NPND urges educators and other professionals who work with people with disabilities and their families to join as a "Friend of FAN." We need all the friends we can get!

Family Action Network

Please complete and return this form to NPND to join FAN. Alerts and newsletters will start arriving as soon as your subscription form is received by NPND.

Yes, I want to help save IDEA!

Name _____

Address _____

_____

Phone (home) _____ (work) _____

Fax _____

Congressional District _____

I belong to an electronic mail system **Yes No**

Name of system _____ E-Mail address _____

___ I am a family subscriber. I have enclosed a check for $25.

___ I am a friend of FAN and equally committed to the fight. I have enclosed a check for $25.

___ I am so concerned about IDEA, I have enclosed an additional contribution of ___.

National Parent Network on Disabilities, 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

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Kyle is the newest regular on THE PUZZLE PLACE, a PBS series teaching preschoolers to celebrate diversity. Kyle, who uses a wheelchair, makes his debut in the "Willing and Able" episode, scheduled to air Thursday, March 9. Check local television listings.

The National Parent-to-Parent Support and Information System (NPPSIS) is a matching service recently funded by a four-year grant from the Maternal and Child Health Bureau. NPPSIS is creating state fact sheets listing health care reform information, resources, government contacts, medical services and parent advocates. They also keep track of children, diagnosed and undiagnosed, whose parents are looking for a match.

NPPSIS tries to match parents with a "veteran parent" who has an older child with a similar condition and is willing to provide guidance and support.

To sign up as a parent in search of a match, a parent willing to serve as a veteran or both—contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513, (800) 651-1151 (V/TTY), or (706) 632-8830 (V/TTY).

Kids' Hall of Fame by Pizza Hut is an annual search for kids up to 14 years of age who have made, or are making, a positive difference for themselves or the world around them. Five Hall of Fame inductees—each receiving a $10,000 post-high school scholarship and a trip to Washington, DC—will be announced in the spring. Runner-ups receive $50 or $100 U.S. Savings Bonds. Nomination forms are available at Pizza Hut restaurants or by sending a SASE by Feb. 28 to Kids' Hall of Fame, P.O. Box 92477, Libertyville, IL 60092. Entry deadline is March 15.

The staff of the EXCEPTIONAL PARENT publishing office in Hackensack, New Jersey joined children, parents and staff for a December holiday party at the Hackensack Medical Center's Institute for Child Development. Toys for the children were donated by Steven Kanor of Toys for Special Children and R.J. Cooper of R.J. Cooper & Associates.

Joseph M. Valenzano, Jr., EXCEPTIONAL PARENT president and publisher, is the fellow in the red suit and white beard. Helping him out is elf Terri M. Sutera, vice president of marketing.

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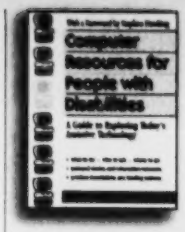

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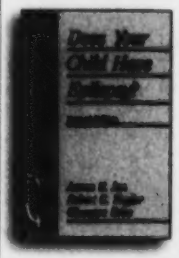

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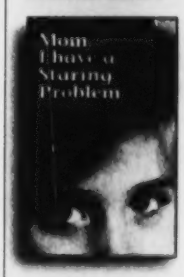

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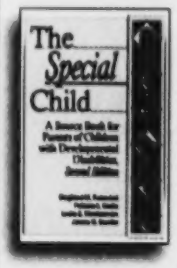

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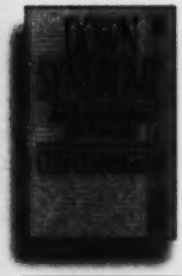

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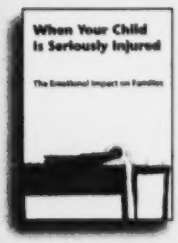

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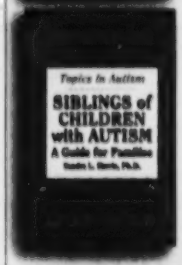

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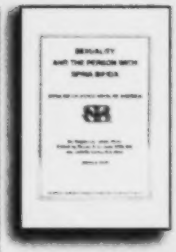

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CHILDREN'S PAGE

ALEX'S PHONE CALL

by Doug Bittle

My little brother is named Alex. He is nine years old and has Down syndrome. Alex went to a special education school for three years and never really had a social life of any sort except with our own family.

Although his old school was good for him when he started there, it changed after a while. It seemed he would be better off with kids who did not all have disabilities. So, my mom decided to have him go to Bethesda Elementary School. Now, he is in a regular fourth grade class. Sometimes an aide helps him when he needs it.

Alex loves skiing. Two years ago, he enjoyed a winter vacation with his family in Crested Butte, Colorado.

Alex and Chris play lacrosse with their cousin, Chris Lyons (back to camera).

Tonight (November 7, 1994), I answered the phone and it was Jeffrey, a new friend of Alex's at his school. He was calling for Alex. What was so significant about this phone call is that it was Alex's first phone call!

One problem is that Alex is not very conversational and when the friend called—just to talk—the friend had to do most of the talking. My mom and I helped Alex out. It was pretty cool that Alex got a phone call from a friend.

Alex smiles for his 1994 school portrait at Bethesda Elementary School.

The kids at the new school also accept and encourage Alex. Last week, he read four sentences in front of the class and the kids in his class all clapped for him. One of Alex's biggest problems is that sometimes he just chooses not to talk although he can understand you. He has always been like this. I think the new school will help him to talk more because he has more friends.

Unlike many children going to school, Alex happily boards a school bus every morning at eight o'clock. Alex is a great little brother and I'm glad he has friends at his new school.

Doug, 12, lives with his parents, Pat and Greg, and brothers Alex, 9, and Matt, 14, in Garrett Park, Maryland. He is in the sixth grade at Tilden Middle School. Doug enjoys sports, especially football, basketball and in-line skating.

THE CHILDREN'S PAGE welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to: CHILDREN'S PAGE, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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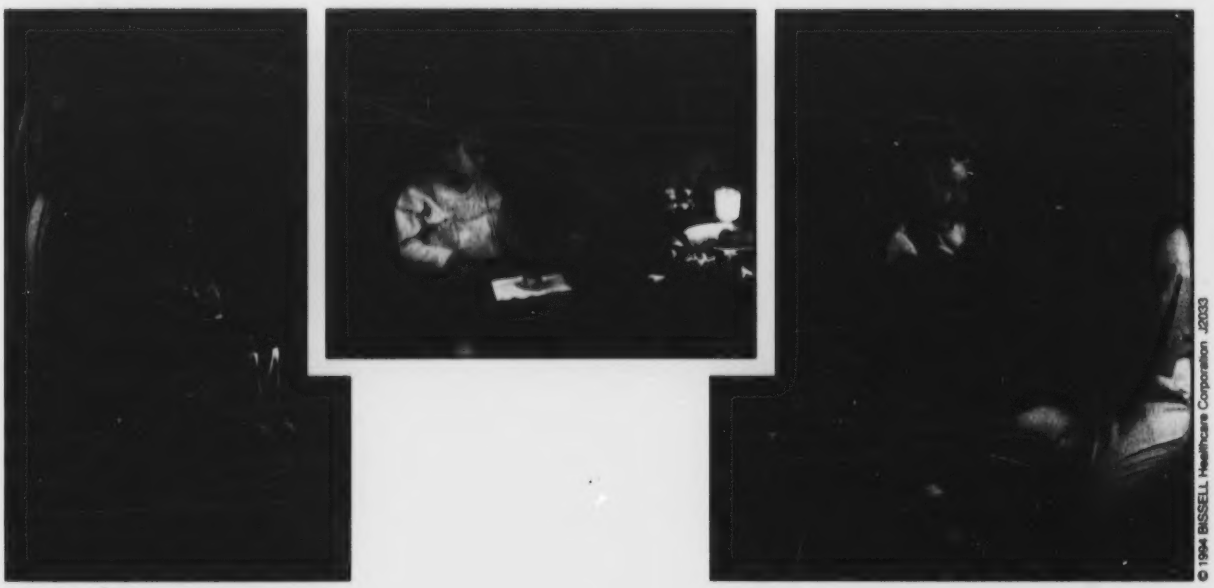

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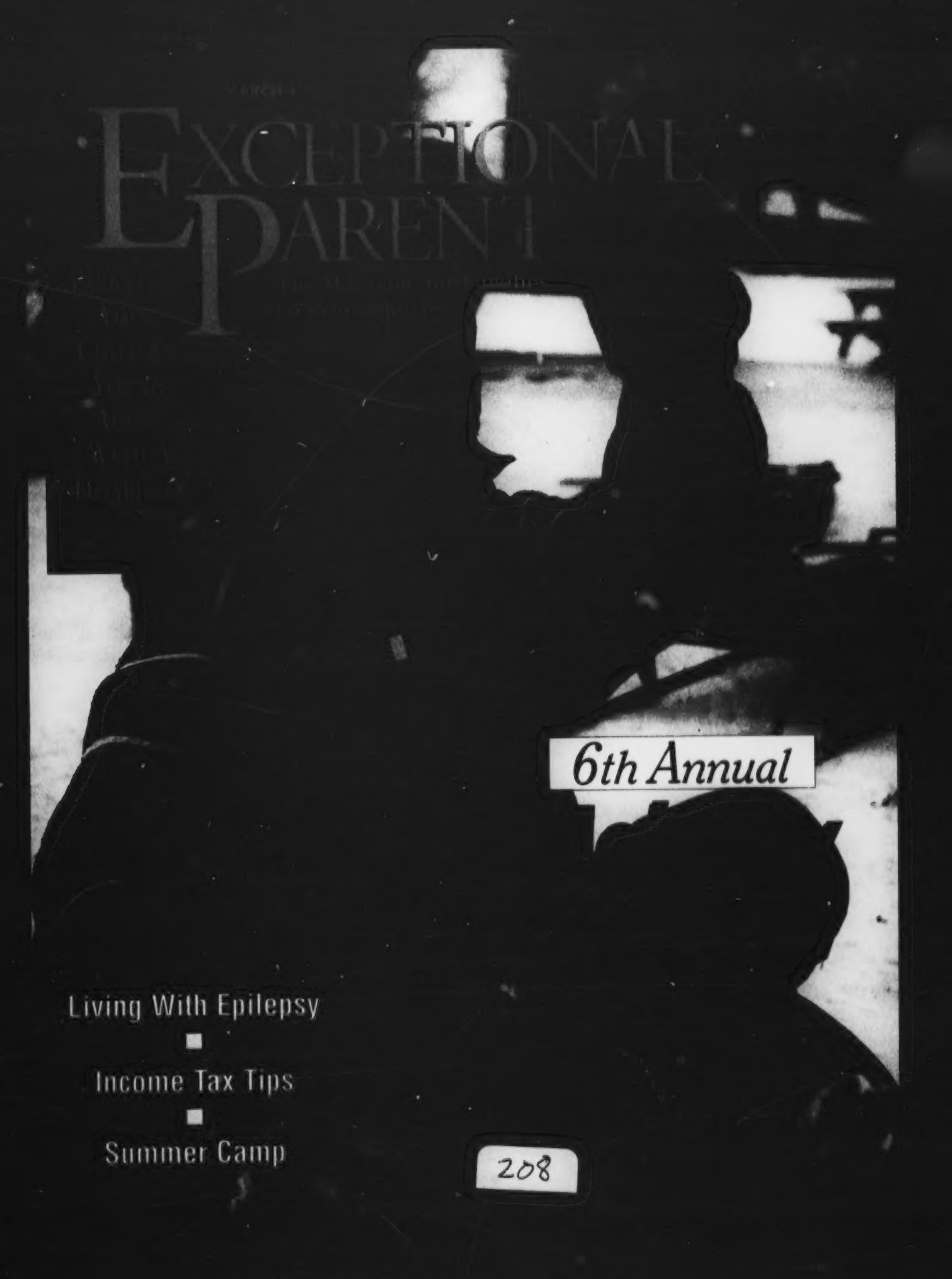

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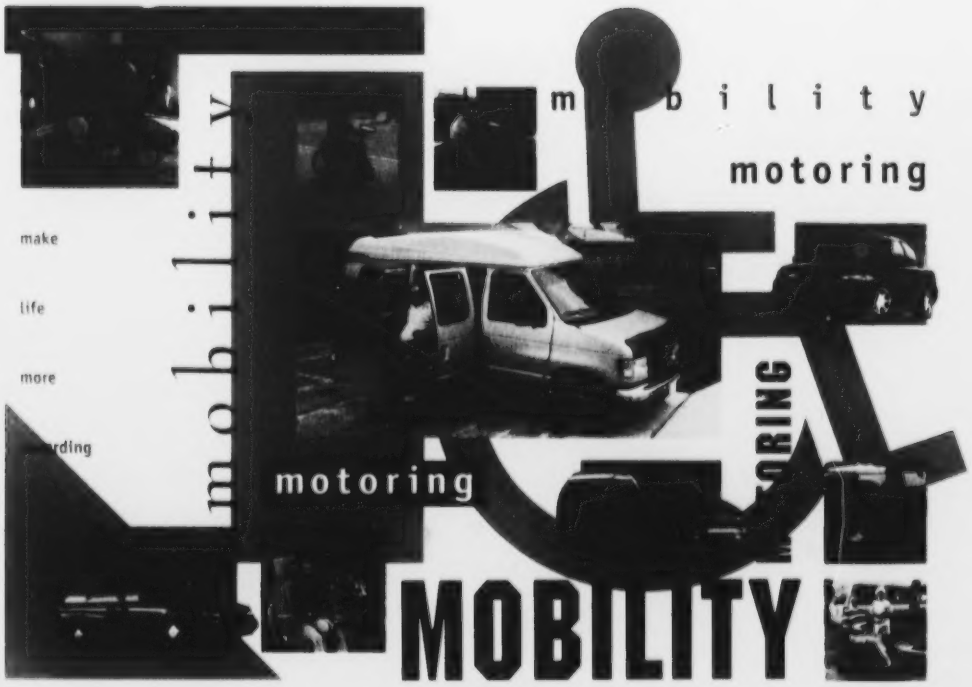

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EXCEPTIONAL PARENT

MARCH 1995
VOL. 25, ISSUE 3

PAGE 25

Cover: *Ten-year-old Clark Byers enjoys a snowy afternoon at a park near his Bloomington, Indiana home. In this issue, his mother, Katharine, describes how the family has learned to live with Clark's epilepsy. See "One Day at a Time," page 19.*

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EDITOR'S DESK

Once upon a time, all wheelchairs looked alike. One size was expected to fit all, and consumers (parents and individuals with disabilities) had little or no participation in the decision-making process.

STANLEY D. KLEIN, PH.D.

Today, many mobility products are available to allow children or young adults with physical disabilities to participate fully in community life. This preponderance of choices has made the selection process more complicated than ever before. Identifying the most appropriate equipment for a child or young adult requires careful assessment and collaboration by parents and professionals.

Our sixth annual mobility issue offers a road map to this process. For help, we turned to Adrienne Falk Bergen, RPT. Adrienne has spent many years answering mobility questions and training therapists and other mobility professionals. With Adrienne's help and the help of her colleagues, we have included articles on the selection process, the roles of the people involved, powered mobility and manual wheelchair maintenance. This issue also includes some personal perspectives from parents and, on the *Children's Page*, from eight-year-old Emily Brush.

Much more than mobility

There's lots more in this issue for parents and for professionals. In "One Day at a Time," Katherine Byers describes how her family has learned to live with her son's epilepsy; in *Role Models*, Tony Coelho shares his experiences as a person with epilepsy.

For families beginning to make summer plans, this issue includes information on camps. And *Youth Connections* explores the transition concerns of teenagers with disabilities and special health care needs and their families.

Feedback

We continue to receive wonderful feedback about our December (1994) issue on religion and our *1995 Resource Guide* (January). We have published some of these responses; we wish we had room for all. Thanks to all who have written and called.

We also continue to receive feedback—largely negative—about the fact that *Exceptional Parent* accepts advertisements from private, special-education programs. It seems that some people concerned with the education of children with disabilities insist that everyone—including this magazine—support the inclusion of all children in public schools. Our perspective is different. Since the first issue of this magazine appeared in 1971, *Exceptional Parent* has advocated for the position that parents are the best experts on their children and are capable of making good choices on their behalf—in education, health care, recreation and every other area. We are also advocates for inclusive education when such programs include the necessary supports for everyone involved. At the same time, we are very leery of programs masquerading as inclusive education—but actually implemented as cost-cutting measures—that fail to provide support for children's individual needs.

On Capitol Hill

In our February issue, Justin Dart's guest editorial ("All Together Now") and *Networking* (from the National Parent Network on Disabilities) expressed concerns that Congress might cut programs supporting the independence of children and adults with disabilities and their families. On the basis of recent news reports regarding proposed changes in SSI (Supplemental Security Income) regulations, we urge readers to contact legislators to let them know that programs like SSI are critical and cost-effective. At the same time, we know some federal programs need improvements; share suggestions for changes with your congressional representatives as well.

EXCEPTIONAL PARENT
The Magazine for Families and Professionals

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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 62. BPA International Consumer Magazine Membership Applied for August 1993.

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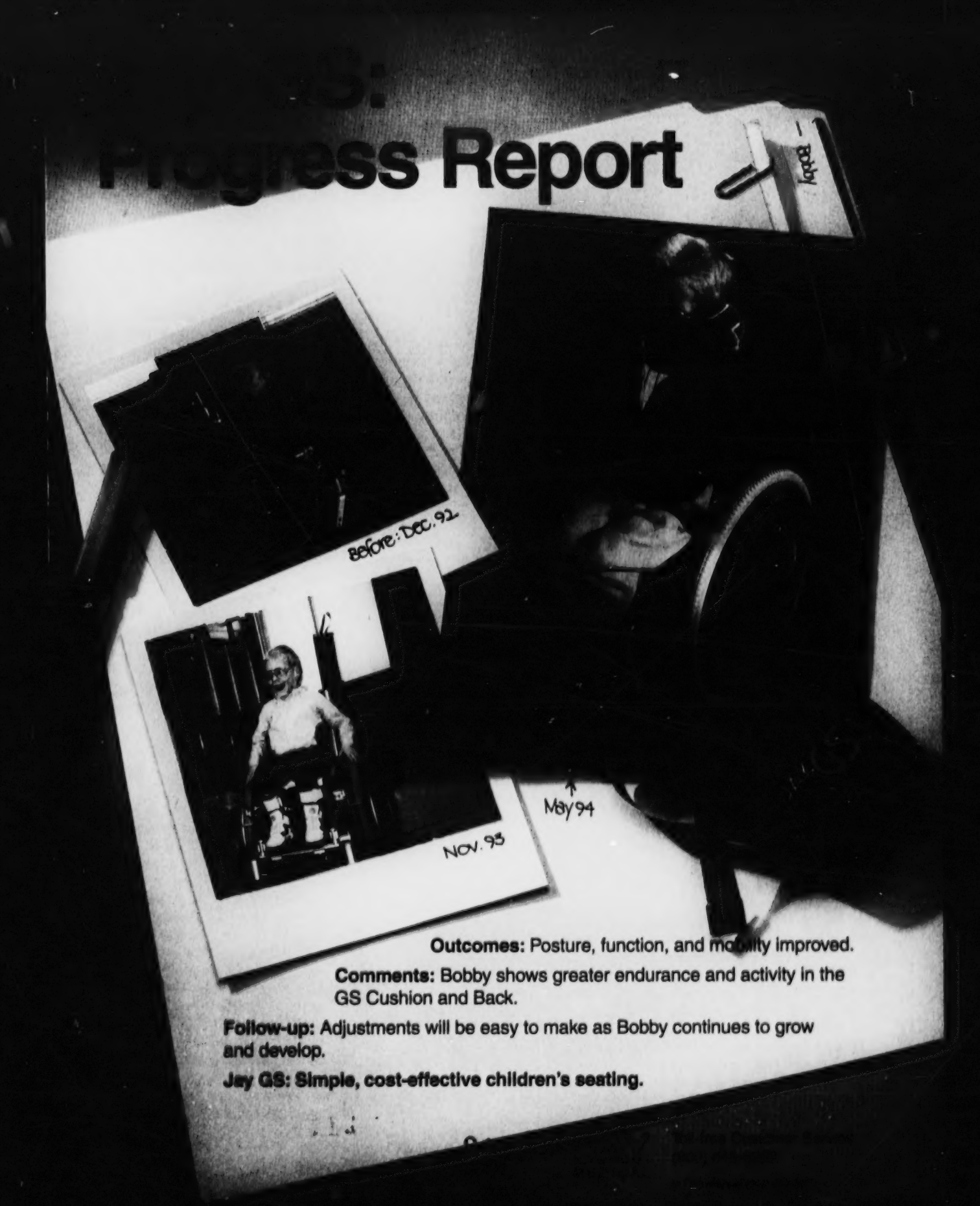
Progress Report



Outcomes: Posture, function, and mobility improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.

LETTERS

Religious Participation for All

The phone rang the other day, and the voice at the other end identified herself as Ginny Thornburgh (author of "For the Love of Peter," December 1994). You cannot imagine my surprise, delight and honor that she would call me just to chat about our special children and the very real need to include them in all aspects of life, especially religion. Her call had been prompted by my letter to the Religion and Disability Program of the National Organization on Disability (NOD), which had been listed in the directory of "Faith Group Resources" in the December issue of *Exceptional Parent*. Although I had read that issue at the end of a long day, I had pushed myself to write to all the Jewish organizations and to the National Organization on Disability. I never realized I was writing to Mrs. Thornburgh! That one call from her erased a lot of the hurt we have felt because of the lack of response from our own religious group.

Although our son attends our temple's religious school, this is more because we sought out a small synagogue that would welcome us as a family rather than the existence of any special accommodations. The December *Exceptional Parent* was a vital, alive issue—we thank you for devoting an entire issue to this aspect of life. My only sense of sadness was that it took a sectarian magazine to provide me with access to these resource organizations; the access did not come from our religious community.

As parents, if we had one wish, it would be to find a way to distribute the December issue of *Exceptional Parent* to all clergy. For all the strides the disability community has made, the greatest barrier is still lack of awareness.

We extend our appreciation for the sensitive way the December issue was handled. The contacts we have made from that issue will keep our fires burning so we can continue to educate those we meet about our special needs rather than just walking away. It can be a never-ending, exhausting task, but we think our children and the world that encounters them will be a little richer as a result.

G.F-H. & G.F-H., California

❑ Bravo to you! What an excellent issue on religion and people with disabilities! My four-year-old son, Bryce, has spina bifida. He is very involved in our church; in fact, church provides most of his socialization opportunities. He asks to go to church almost every day. During his last IFSP (Individual Family Service Plan) meeting, a teacher commented that Bryce got a lot of socialization from being out in the community and in church. At the time, I thought, "Hey, we ought to write that in as part of the plan." Next time, we will!

One program that should be included in your directory of "Faith Group Resources" is the AWANA Clubs International (One East Bode Rd., Streamwood, IL, 60107; 708/213-2000, voice). It is like a Christian scouting program, complete with uniforms and awards. It is an inter-denominational Protestant group that gives charters to individual churches. They have a "Friends" program for children with disabilities. Parents can contact them for more information and to find out which churches in their area sponsor a club.

Bryce loves his AWANA "Cubbies" Cub. Before I end this letter, I have to share a story about him. Bryce was learning a Bible verse for his Cubbies club: "Children, obey your parents." I was so proud of him for learning it and wanted to show him off to some friends. So I asked him to say his verse. He promptly and clearly said, "Children, open your presents."

Thanks again for an exceptional issue!

Rachel Olstad, Talent, Oregon

From left, Bryce Olstad, Ethan Ungala, Michaela Nuss and Cassie Ekwall listen to a story during a meeting of the AWANA Cubbies Club at Ashland Bible Church in Ashland, Oregon.

Success in Funding Van Adaptations

I'm writing in response to "Buying and Converting: What you need to know about van lifts and ramps" (December 1994).

Our four-year-old daughter, Jocelyn, has Walker-Warburg syndrome and uses a wheelchair. She weighs 45 pounds, and we are no longer able to get her in and out of a car seat.

We already had a mini-van when I began my search for funding to get portable ramps and a tie-down system. I was told the total cost for purchase and installation would be $690.

I began calling social service organizations and fraternal clubs to see if financial aid was available. I spent more than a few hours on the phone, but was very successful! I was able to get money from Easter Seals, and the United Cerebral Palsy Association. This left our portion at $40.50—very affordable.

I wanted readers to know that help is out there, if you're willing to spend some time finding it. Many of these organizations will also assist with funding for lifts.

J.F., Indiana

Tell us about...

...helping your child make friends.

Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

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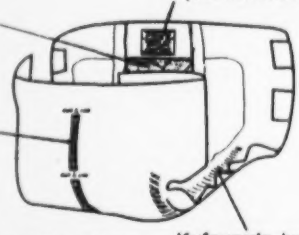

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LETTERS

Felbatol

I deeply sympathize with the parents who were told by their daughter's neurologist that she should be weaned off Felbatol ("Ask the Doctor," December 1994). I am the parent of a seven-year-old son who has been on Felbatol for the past 13 months with dramatic results. While I support Dr. Hirsch's response, I think the parents should be advised to seek additional information to help them make the best decision for their daughter, in conjunction with their neurologist.

Our son had been taking Felbatol for nine months when the makers of the drug first began warning doctors of the risk of aplastic anemia and liver failure. We were terrified to learn that these very serious complications had been linked to this "miracle drug." Blood tests were immediately ordered for our son. Fortunately, they revealed no problems, and our son's neurologist recommended continuing the Felbatol.

Even though I trusted our neurologist, I wasn't ready to blindly accept this advice. This was my son's life we were risking, and even though stopping Felbatol may have meant the return of our son's uncontrollable, complex grand mal seizures, we sought to become as informed as possible before making a final decision. The Epilepsy Foundation of America was an excellent resource. After confirming, or in some cases correcting, what our neurologist had told us, the foundation gave us written, detailed information about the reported complications, the symptoms we should watch for and the precautions we should take. They even offered to contact our son's neurologist on our behalf.

Ultimately, we did accept our neurologist's advice to continue the Felbatol with frequent blood tests. Our son has now been free of grand mal seizures for more than a year with no sign of side effects.

D.L.P., North Carolina

Editor's Note: Readers may contact the Epilepsy Foundation of America at 4351 Garden City Dr., Landover, MD 20785-2267, (800) 332-1000 (voice), (800) 332-2070 (TTY), (301) 577-4941 (fax).

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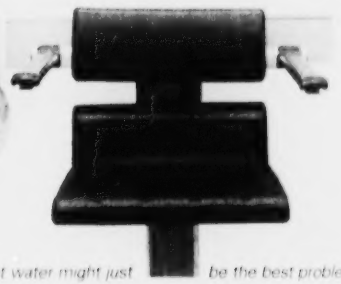

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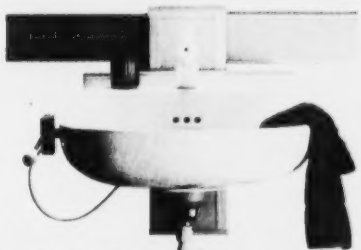

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Circle # 175

SEARCH

Partial Monosomy 10/Partial Trisomy 15

Our 31-month-old daughter has partial monosomy 10 and partial trisomy 15. She has cardiac problems and global developmental delays. She does not walk or talk. We are interested in contacting parents of children who have the same condition.

S.M., Georgia

Near-drowning

Six years ago, my son nearly drowned. He survived, but remains comatose. I have never seen letters from parents of similar children. I know most children don't survive this type of accident, but I am sure many do. I would like to know if anyone is doing research on this type of anoxic brain damage.

S.C., Florida

Persistent ATNR

I have a 17-month-old son with cerebral palsy. He has a very persistent asymmetrical tonic-neck reflex (ATNR). This causes his right hand to constantly dig into the side of his face. I have to hold his hand during play, therapy and feedings. This is very frustrating for both of us! I would like to hear from other parents who have experienced this problem and may have some advice.

T.W., Iowa

Undiagnosed

I have been trying to find a diagnosis for my daughter, Amanda, since her birth in September 1992. She was born with extremely low muscle tone, dislocatable hips and hypermobile joints. To resolve her hip problem, she wore a Pavlik harness until she was four months old. She started physical and occupational therapy at eight months of age and has continued to make progress in her physical development. She walked independently, with the use of ankle-foot orthoses (AFOs), just a few days before her second birthday.

Amanda is a bright and happy child who has excellent language skills. She has had echocardiograms, blood tests for muscle diseases, an electromyogram (EMG), nerve-conduction testing, DNA testing and ophthalmology exams. All results have been normal, with the exception of the EMG, which was scored as "borderline abnormal."

Following the abnormal EMG, we proceeded with a muscle biopsy. Based on the biopsy, doctors have said they think she has Duchenne muscular dystrophy. I have difficulty accepting this diagnosis because I understand that this type of muscular dystrophy is rare in females, is not evident at birth and is diagnosed with greatly elevated creatine phosphokinase (CPK) levels. Amanda's CPK level is within normal limits.

I am tired of hearing doctors say, "I have never seen a child quite like this before." I have a strong feeling that one of the readers of *Exceptional Parent* has seen a child like Amanda, and I would love to hear from anyone who might have some information to share.

D.N., California

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The Magazine for Families and Professionals
Parenting Your Child With a Disability

- ***To reach out to parents of children with disabilities and special health care needs.***
- ***To empower mothers and fathers by providing practical information and emotional support.***

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SONY

T-120

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VHS

Congenital Hyperphosphatasia

Our daughter has been diagnosed with congenital hyperphosphatasia, a metabolic bone disorder. She is also non-verbal and has severe intellectual disabilities.

When she was younger, she broke her legs several times, including both femurs. Her bones are becoming more deformed as she gets older. She can still walk, however, we recently ordered a wheelchair to use for longer distances. She communicates her basic needs with gestures and an Introtalker augmentative communication device.

We would like more information on this disability. She can't tell us what bothers her joints and bones; we would like to hear from anyone who could tell us what we can do to make her more comfortable.

M.B., Iowa

Chromosome Five Deletion

Our 11-year-old daughter has a partial interstitial deletion of the long arm of the fifth chromosome. She is mentally retarded and has physical disabilities. Pneumonia is a constant threat because she cannot move around except for rolling. We want to share experiences with other parents of children with the same condition.

B.B., Ohio

Chromosomes Two and Ten

My four-year-old daughter has been diagnosed with a chromosome abnormality involving a duplication of material from the long arm of chromosome 2 and a deletion of material from the short arm of chromosome 10.

My daughter has low muscle tone and delays in all developmental areas. She has a kidney reflux and is being monitored by an ophthalmologist for the possibility of strabismus. We would like to hear from other parents who have a child with a chromosomal abnormality involving these two chromosomes.

K.S., Oregon

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

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☐ Morton-Young, Tommie—**AFTER-SCHOOL AND PARENT EDUCATION PROGRAMS FOR AT-RISK YOUTH AND THEIR FAMILIES: A Guide to Organizing and Operating a Community-Based Center for Basic Educational Skills Reinforcement, Homework Assistance, Cultural Enrichment, and a Parent Involvement Focus.** '95, 148 pp. (7 × 10), 1 il. Cloth—$37.95, paper—$22.95.

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Circle # 25

RESPOND

Disability Awareness in Public Schools

M.G. (October 1994) has a 10-year-old son, Allan, with Asperger syndrome (a type of "high-functioning" autism) and some neuromuscular problems. He does well in regular science and social studies classes. M.G. wanted to hear about disability-awareness programs that have been used successfully in public schools to teach all students about disabilities.

I just want to add my comments on the importance of disability awareness in public schools. My son is 12 years old and has multiple disabilities—most of them "invisible"—including Tourette syndrome (TS) and obsessive-compulsive disorder (OCD). He is on medication for the TS, but has very minor motor tics. He is impulsive and has compulsive behaviors. All in all, he can be a "difficult kid," particularly in unstructured situations like recess and lunch.

Before he started at a new school this fall, I made a point of meeting his teacher and the school counselor. I gave them a video and written materials on TS/OCD and a written narrative on how all this information applied to my son. I explained that he needed extra help and supervision.

The first week or two seemed to go well. My son talked about all the new friends he had made and how much he liked his new school. Then the predictable decline began as his behaviors alienated the kids in his class who had no reason to try to understand him, since they did not know about his diagnoses.

I could see my son becoming increasingly tense, and I worried that if pushed far enough, he would strike out and hurt someone. I went to the school and talked with the principal. I told him what was happening and gave him a short videotape on TS that could be shown to the class. My parting comment was that some intervention needed to happen soon because I could see trouble on the horizon. That very day, my son and some other children were involved in a major fight on the playground. Everyone was hauled to the principal's office, crying and upset.

Fortunately, the principal had been prepared, and after settling the children down, he met with the school counselor, classroom teacher and my son to set up a class meeting for the next day. In that meeting, they planned to show the video on TS, allow the children to ask questions about the condition (including questions directed to my son who would be supported by his case manager), and have the children brainstorm ways to help my son at times when

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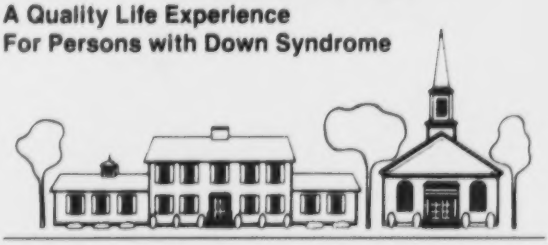

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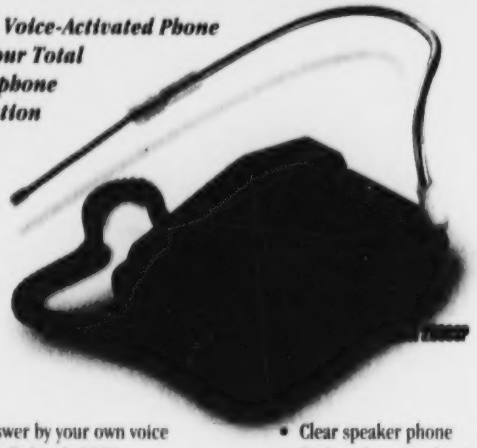

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Circle #91

he seemed to be "losing it." He came home that day happier than he had been for weeks. He seemed relieved about finally getting everything into the open.

The next day was no disappointment. The class watched the video intently and had many questions about TS—When did you know you had it; can other people catch it; will you always have it? They also had many good ideas about supporting my son—from verbal reminders to him, to educating kids in the other classes about TS.

The effects of that day have been remarkable. My son is working hard in school, rarely has any difficulty with his peers and goes to school happily every morning. My best reward came one morning soon after the class meeting. As he was eating breakfast, he turned to me with a big smile and said, "Mom, all the kids in my class play with me!"

C.R., Oregon

Loud Noises in Public

G.W. & J.W. (December 1994) have a six-year-old daughter, Kaitlyn, with severe intellectual disabilities. Rett syndrome has been ruled out, and Kaitlyn's parents do not believe she is autistic. Kaitlyn does not talk, but makes loud noises and high-pitched screams; her parents worry about how these noises will be handled when she starts kindergarten next year. They wanted to hear from anyone who has dealt with a child who has similar characteristics, and were especially interested in suggestions for getting Kaitlyn's noises "down to a reasonable pitch."

I do not have the answer to your question but our daughters seem similar so I decided to write. My six-year-old daughter, Katie Lynn, also has severe intellectual disabilities. The possibility of an autism diagnosis has come up several times. Soon, we should be receiving the results of a recent autism evaluation.

Like your daughter, Katie Lynn is completely nonverbal. When she is happy or excited, she flaps her arms and utters a high-pitched scream. Depending on the situation—for example, in church or at her sister's choir performances—this behavior can be embarrassing for the family. But as odd as this behavior might seem to the general public, these screams are Katie's only means of communication. It is her way of expressing pleasure,and I will not discourage this behavior just so she can fit society's picture of normality. Katie is forced to modify her behavior in other areas; we have decided that this is one area in which society will have to make the adjustments. In situations where her utterances are disturbing to a group of people, my husband or I will take her out of the room until she is calmer.

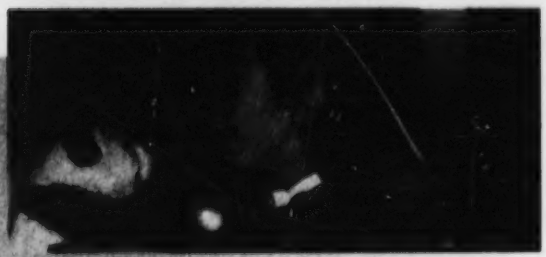
Katie has received services in public schools since she was one year old. This year, for the first time, she has been mainstreamed into a regular first grade class for part of the day. We have visited the school several times to discuss problems that the teachers are having with her, but her loud vocalizations have never been an issue.

D.T., Texas

Familiar Faces

Nicholas Tietje, 10, shares the first spin around the block on his new bike with sister Emily, 5. Nicholas, a fifth-grader at Byron Elementary School in Tualatin, Oregon, has cerebral palsy.

"It's for you, Sis!" Eighteen-month-old Victoria Price of Spring Lake Park, Minnesota loves "talking" on her play telephone with a little help from big brother and best buddy Justin. Mom Laura writes, "Thanks for the opportunity to share my children with others who understand that children are beautiful even if they need extra equipment or their eyes cross."



Three-and-a-half-year-old Timothy Alexander Crews died last year, shortly after Christmas. "Alex," who had centronuclear myopathy, loved listening to music, riding in the van, wheeling around in his wheelchair and snuggling with Mr. Panda. He communicated fluently using sign language and attended an Easter Seal Society preschool near his home in Mobile, Alabama. His mom, Beverly, remembers Alex as "a bright and happy child who touched many people."

Would you like to share a favorite candid snapshot or slide *of your child and/or family with other readers of* EXCEPTIONAL PARENT*? Send it to: Readers' Photos,* EXCEPTIONAL PARENT*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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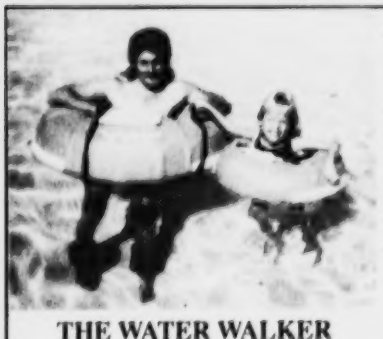

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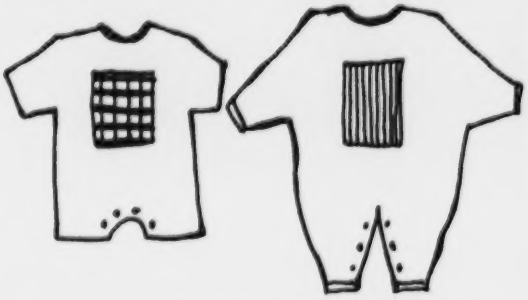

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One Day at a Time

A family learns to live with epilepsy

by Katharine Byers

The day started like most Saturdays with Clark jumping into our bed for a brief snuggle before watching "Bucky O'Hare." It ended in the intensive care unit with Clark on a ventilator, physically exhausted from his first seizure since infancy. Our seven years as parents had not prepared us for the change this event would bring to our lives.

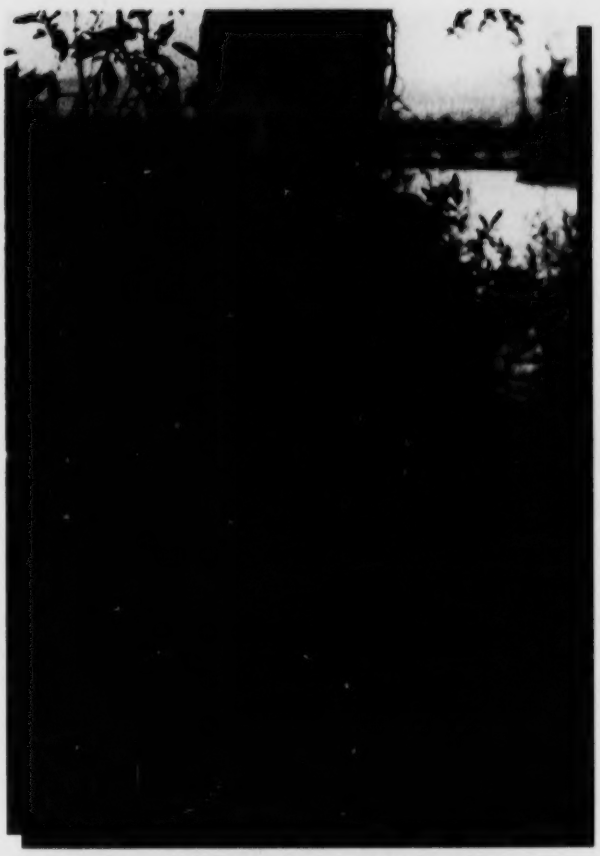
After breakfast, Clark and I had set off on errands—to the library for new books, to the nursery to get marigolds for the garden, to the mall to find a blue dress shirt for Clark to wear in his role as narrator of next week's kindergarten production of "The Three Little Pigs." It was hectic but fun as we discussed upcoming T-ball games and school activities as we drove. Back at home, Clark seemed quiet and subdued. When he said he was not hungry for dinner, I knew something was wrong. I felt his forehead. He was burning up with fever!

After a cool bath and Tylenol, he lay down for a nap on our bed. An hour later, his fever had come down. As I turned him over to carry him to his own bed, he started jerking violently, first on his right side and then his whole body. I knew it was a seizure and shouted to Jim to call 911. I cradled Clark as the jerking continued. His head and eyes turned to the side. He started smacking his lips and his breathing became shallow. I kept talking to him, "Clark, it's going to be OK. The ambulance is coming. Just keep breathing. Relax, honey. Relax. It's OK." I'm not sure if my words were meant to reassure him or me.

A trip to the ICU

The ambulance seemed to take forever, and Clark was still actively seizing when the EMTs arrived. Jim and I answered their questions and gave a short version of Clark's complicated medical history—prematurity, necrotizing enterocolitis requiring the removal of a substantial portion of his intestines, mild cerebral palsy, asthma. It was the first of several times that evening we would recite the litany of his medications and major surgeries. In shock, we reacted calmly, automatically, trying to help without getting in the way of the EMTs.

GRADUALLY WE REALIZED THAT CLARK'S FIRST SEIZURE WAS NOT AN ISOLATED EVENT, BUT THE BEGINNING OF A NEW CHALLENGE.



Clark, 10, shows off the whitefish he caught at Squanga Lake during a family camping trip to the Yukon last summer.

The trip to the hospital in the ambulance was like being under water in slow motion. I kept thinking my watch had stopped as I glanced at it every minute. Why was it taking so long when the speedometer said we were going 40 mph? By the time we arrived, Clark had stopped breathing and the EMTs were puffing air into his lungs. After we recited his medical history for the emergency room doctor, Jim and I sat on the couch in the waiting room, holding hands.

Turning to Jim, I said, "I know this may be premature, but I need to say this: Are we in agreement about no heroic measures?"

"Yes," he said quietly, and squeezed my hand.

The social worker returned with coffee, and we talked while waiting for the medical team to try to stop Clark's seizure and stabilize his condition. More than an hour later, we were allowed to see him.

Sedated from all the medication it

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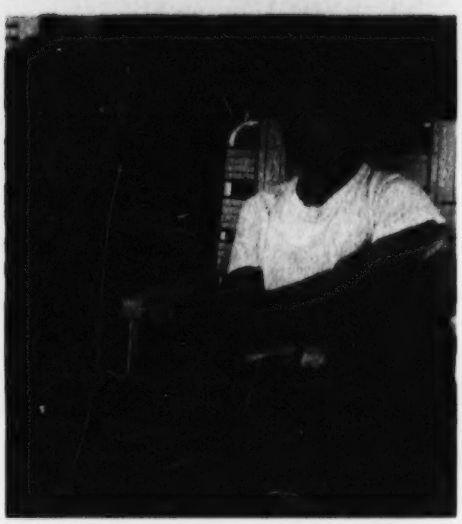

had taken to stop the status epilepticus, Clark was too exhausted to breathe on his own. He remained on a ventilator overnight with us by his side. We watched anxiously, alert for any indication of possible brain damage from such a prolonged seizure. When he started breathing on his own and asking for food, we knew he was better. Several days later, he came home with a diagnosis of an atypical febrile seizure and a prescription for Depakote.

A new challenge

Life quickly returned to normal. There were no more seizures over the summer, and we began to relax. But in the fall, Clark started having seizures again, always in the mornings, but never again associated with a high fever. There were more calls to 911 when his then-diagnosed focal seizures generalized and impaired his breathing. There were more hospital stays, changes in medication, EEGs and visits to the neurologist.

Gradually, we realized that Clark's first seizure was not an isolated event, but the beginning of a new challenge. Clark had a seizure disorder, and epilepsy does not go away. It took a while for us to be able to say "epilepsy" out loud, with the conviction to fight the stigma still attached to this disability.

"Seizures stink like poo-poo!"

Nothing in my professional career as a social worker or in my work with parents of children with developmental disabilities had prepared me to live with epilepsy. Nothing in our previous experience with Clark had prepared us for the anxiety of constantly being on alert. We had survived his premature birth and the worries of his first critical illness when he was given a 40/60 chance of survival. We had dealt with tube feedings when he lost his suck reflex. We had adjusted to mist treatments to keep his asthma under control. We had become accustomed to at least one hospitalization a year and frequent visits to the pediatrician during the cold winter months. We had gotten used to ongoing physical and occupational therapy to counter the effects of his mild cerebral palsy.

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Now we had a new label, a new medical specialty, new tests and new medicines to learn about. I knew I would like Clark's first neurologist when he wore a Mickey Mouse T-shirt at our first meeting in the hospital. The book he recommended provided helpful information but also added to our anxiety when we learned that controlling seizures was more trial and error than exact science. Learning that Clark's seizures might get worse before they got better made us feel we were on an out-of-control roller coaster. Learning that children who have seizures often have learning problems was devastating.

We were angry, confused and worried, and when we took the time to listen, so was Clark. During one early visit to the neurologist, he said angrily, "Seizures stink like poo-poo!" and the doctor agreed. Clark understood more than we first gave him credit for; we have since learned to talk to each other about our feelings. Only if we accept the anger and lack of control we sometimes feel, can we move to exert what control we can.

One day at a time

As a family, we are learning to live with epilepsy. It has been five years since Clark's first frightening seizure, and he has been seizure-free for more than two years. Still, school personnel, parents of friends and Clark all know what to do in case a seizure begins. Clark reminds us when it is time to take his Dilantin, and we make sure he gets enough rest.

We have learned not to let the possibility of seizures define our lives or Clark's. We are cautious, but allow him to participate in normal 10-year-old activities—Boys' Club basketball, sleepovers, swimming in the pool. We took a long-anticipated camping trip to the Yukon last summer.

Clark is not an "epileptic;" he is a young man who has seizures. He has successfully confronted situations many adults have never had to face. Though mature beyond his years in many ways, we are determined that seizures will not rob him of as normal a childhood as possible. We are learning to live one day at a time, to enjoy each day fully and completely, and to stop putting important family activities off because we can never predict with certainty what tomorrow will bring. **EP**

Katharine Byers lives in Bloomington, Indiana with 10-year-old Clark, and Jim, her husband of 25 years. Kathy has administrative and teaching responsibilities in the undergraduate social work program at the Indiana University School of Social Work. She is active in the National Association of Social Workers and serves on the Advisory Board of the Institute for the Study of Developmental Disabilities.

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Mobility—"The devil is in the details"

The purchase of mobility equipment for a family member with a disability is sometimes compared to the purchase of an automobile. This comparison is not particularly helpful because of the vast differences in industry economics, available choices and the degree to which the consumer is dependent on the product for day-to-day life.

A car buyer can choose to purchase an automobile from one of many companies offering a variety of products at a wide range of prices. It is relatively easy to become informed—a great deal of information is readily available from both automobile manufacturers and independent sources. A car buyer also has some choices about how to pay for the purchase. Or if the consumer doesn't want to *buy* a car, leasing is an option. Some consumers may decide that a used car is sufficient for their needs. Or, particularly in urban areas, a consumer can decide to forego automobile ownership and make use of public transportation.

The consumer with a disability who needs mobility products (wheelchairs, lifts, vans and ramps) does not have the same kinds of choices. To begin with, he or she cannot decide to go without mobility equipment. Even though public transportation options for people with disabilities are expanding, the individual still needs at least one wheelchair, stroller or scooter. While there are many wheelchair choices for the consumer, there are few financial options. Usually, a new wheelchair is purchased by the consumer or a third party. The consumer rarely has the opportunity to purchase a used wheelchair, to lease a new or used product or to finance a purchase over time. And, unlike automobiles, wheelchairs are rarely resold and cannot be "traded in" on a new one. Finally, in terms of actual dollars, the price of a new powered wheelchair or scooter for an individual with a disability may exceed the price of an automobile that transports an entire family.

These factors and others lead to a complex relationship between consumers, manufacturers and retail distributors of mobility products. To most consumers, prices seem too high. At the same time, many manufacturers and retailers struggle for financial survival.

Manufacturers

I have met many manufacturers of mobility products since *Exceptional Parent* began in 1971. When a parent of a child who needed a wheelchair explained the need for consumers like himself to have access to advertisements and other information about products, the magazine began to actively solicit product advertising. Over the years, we have learned the

"Hop On!"

Our daughter, Stephanie, was diagnosed with Werdnig-Hoffman disease at 16 months of age. This neuromuscular disease weakens her arms, legs and torso, severely impairing her mobility.

Stephanie is a very bright child. We felt that independent mobility and socialization were very important. With the help of her physical therapist, we pursued a motorized wheelchair.

When Stephanie was 21 months old, one of her doctors told us that she was too young to operate a motorized chair. Using a "loaner" chair, Stephanie showed her how easy it was. We were also told that the insurance would never approve it. Well, it took a while, but she received her wheelchair when she was two years old.

Stephanie is four years old now. The last two years have been wonderful for all of us. We enjoy seeing Stephanie explore her environment and test her boundaries. She is able to participate in activities with her typical peers. She likes to tell the neighborhood kids to "hop on" the back of her chair for a cruise up and down the block.

There have been some drawbacks. For example, we now have less control over her. When she is in a defiant mood, she "runs away" from us.

One time when we picked her up from preschool, her teacher told us that Stephanie got a time-out for running over a teacher. The teacher had leaned over to tie her shoe and Stephanie couldn't resist the target.

Last year, Stephanie went trick-or-treating in "wet" weather and short-circuited her wheelchair. She "shorted" her chair again, by going through the sprinkler at the private preschool she attends. It has all been worth it though, to see her interact with other children. We wanted her to be just like her peers without disabilities, and she is.

Last May, Stephanie was the flower girl in her aunt's wedding. She drove down the isle proudly and participated in the entire ceremony. She did such a good job that she has been asked to be the flower girl in another wedding next August.

Even though we realize Stephanie will always have some limitations, we want to help her develop a sense of independence and the knowledge that she can continue to be successful at her own rate.

—Sharon Royster
Hudson, Ohio

value of responsible advertising to parents and professionals.

Most of the manufacturers I have met became interested in this field as the result of a personal or family need. Often starting on a kitchen table, or in a basement or garage, individuals slowly created businesses. With talent, creativity and dedication, some individuals have built successful businesses; a few have built large corporate enterprises. It is not my intention to glamorize individuals or companies or apologize for the cost of products. Rather, I want readers to know that most of the manufacturers I have met over the years are responsible, caring people who want to improve people's lives. At the same time, these individuals also want to make a living.

Consumer Input

In preparing this issue, we invited comments from manufacturers about how users, parents and professionals can make their ideas and opinions known to product manufacturers. Manufacturers told us they welcome input because they need to know whether they are meeting customers' needs and want help in improving and refining products. However, manufacturers reminded us that new product development is a slow and costly process and that "the devil is in the details." A wonderful idea may take a long time to be transformed into a viable product.

Some manufacturers send out questionnaires, hold focus groups and solicit feedback at meetings of professionals and consumers. All asked me to convey to our readers that they welcome ideas and suggestions. In fact, most suggested that top management individuals within these companies were eager to hear feedback directly from parents and professionals.

Rehabilitation engineering centers at universities and hospitals can also play a role in product development. Parents and professionals can discuss ideas and questions with experts in these settings. We received a number of examples of this process and have included one in this issue (See "Kyle's New Bike," page 38). When there seems to be a sufficient market, the products developed at these centers may become commercially available.

One of our goals in this issue is to explain the different roles of the individuals involved in mobility decisions so consumers and professionals can be well-informed as they consider possible choices. At the same time, we have illustrated the complexity of the process and the need for comprehensive assessment of a user's needs before decisions are made. The process is not an easy one, and it cannot be "simplified."

–S.D.K.

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Circle #151

Obtaining Specialized Equipment

Who's who in the process

by Adrienne Falk Bergen

There is an evergrowing amount of specialized equipment available for children with special needs. The challenge lies in selecting the most appropriate product. How do you choose the right piece(s)? Who can help the family through the maze?

The process of obtaining specialized equipment always begins the same way—someone notices that a problem exists. It may be a child who is uncomfortable or sits poorly, or equipment that no longer meets the child's needs. If a caregiver, family member or teacher is the first to recognize a problem, they should report it to the child's primary therapist. If the family is not aware of the problem, they should be notified first. For a child who is not receiving ongoing therapy, the problem should be reported to the person or facility that manages the child's equipment needs.

If the child's primary therapist receives a report of a problem, he or she can usually decide if it can be solved on-site with simple adjustments using available tools. If not, the therapist may call a team meeting, approach the equipment supplier for suggestions or refer the child to the medical clinic that manages his or her equipment needs.

Even if the therapist refers the child to another site, it is important that he or she be involved in the assessment process so the recommended equipment is appropriate for reinforcing the child's therapy goals. The child's primary therapist and the child's family are the experts on the child's daily life and his or her living and learning environments. The person doing the assessment may see the child in an unfamiliar setting for a relatively brief visit. Involving the child's family and primary therapist(s) in the assessment process may take extra time, but using input from varied sources leads to a better result.

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A Black Tie Affair

When Todd was 13, he celebrated the arrival of his new chair by renting a tuxedo—without even telling us—to wear on his first day using the chair. He was so proud. He wanted to show it to the world and especially to all his friends at the Summit Mall in Akron, Ohio, where his dad owns a tobacco store.

Since Todd was 10, his dad has been letting him roam the mall. He began by visiting the store next to his dad's. He gradually made his way around the whole mall. He has friends everywhere who watch out for him, so potential dangers have been minimized. Todd even bought a popcorn machine and earns spending money by selling popcorn and running errands, such as delivering lunch to clerks stuck in their stores all day.

Todd Carson, then 13, rented a tuxedo to celebrate the arrival of his new wheelchair.

While Todd, now 16, has multiple disabilities due to a grade IV intraventricular hemorrhage shortly after birth, he is very aware and extremely verbal. He enjoys discussing sports statistics with the guys at the tobacco shop. After getting to know Todd, people see past the wheelchair and discover the unique person.

Todd's wheelchair has allowed him to enjoy baseball games, basketball games and wrestling tournaments. He has "danced" all night at a sorority-sponsored dance marathon at the mall to earn money for charity. He makes "dates" with special friends and takes them out to lunch at the mall with money earned from his popcorn sales. He has participated in the Special Olympics and won first place for Frisbee throw and wheelchair slalom.

The wheelchair lets Todd be one of the kids on the block, riding up and down the street or pulling his little brother in his wagon. He has felt useful by hauling branches when the family does yard work. He has taken off by himself down a rugged path in northern Canada where we go camping—with me watching over him by jumping behind trees.

Todd's wheelchair has given him an incredible sense of independence. To someone who must depend on people for every other need, such as feeding, dressing and toileting, having one area of your life where you're in control means the world. No wonder Todd's last words every night are "Did you plug in my chair?"

—Jean Carson
Clinton, Ohio

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Who's who?

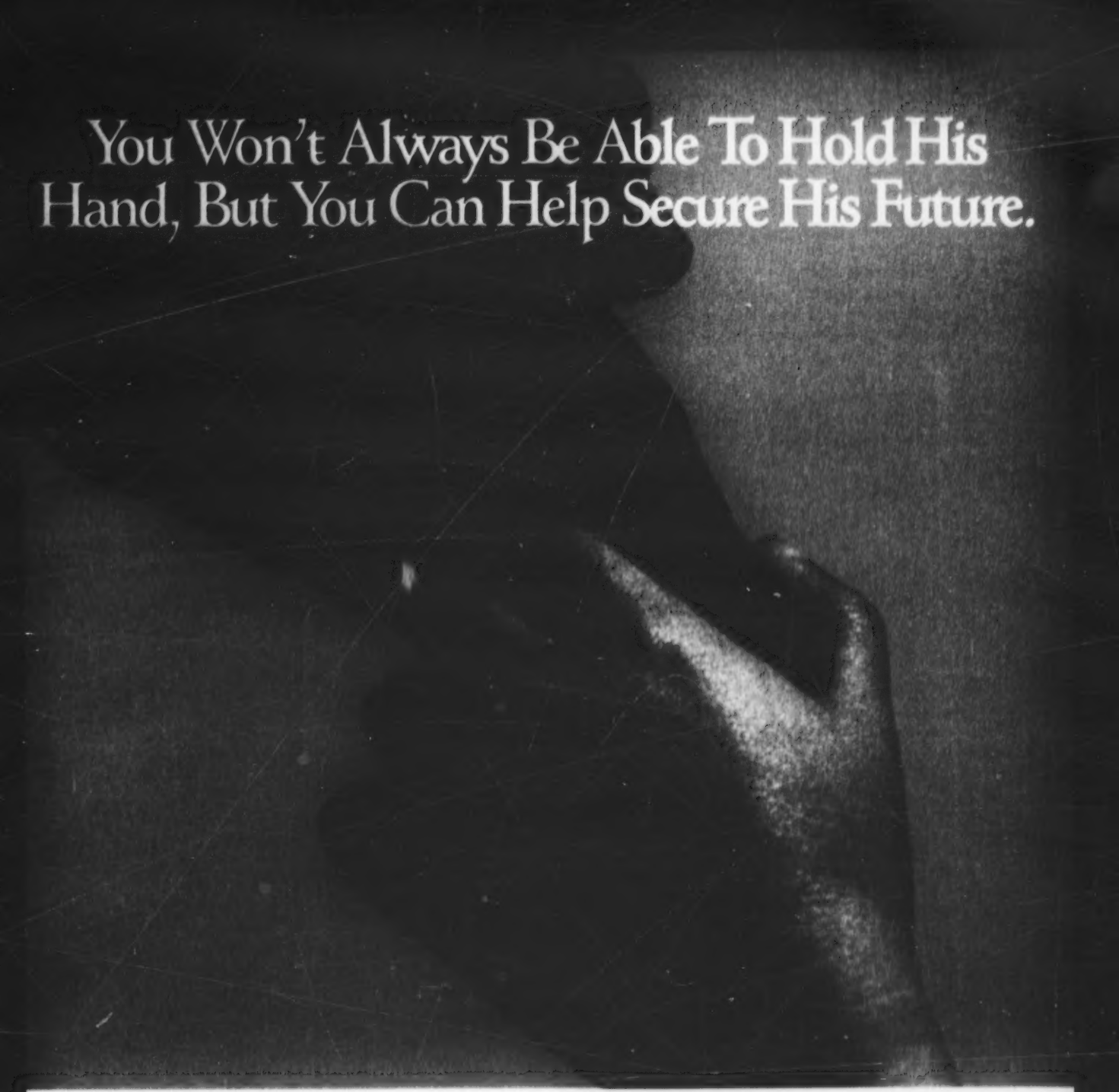
It is important for everyone to understand the roles of the various people involved in the problem-identification, assessment and equipment-provision process. This will help each team member know where to go for the information they need along the way. The sidebars to this article, "Our Child Needs a Bath Chair" and "Our Child Needs a Wheelchair and Seating System" illustrate how parents and professionals work together to purchase mobility equipment.

- **User:** The person who actually uses the equipment.
- **Family:** Parents, grandparents, siblings, legal guardian and/or significant others who are directly related to the user of the equipment.
- **Caregivers:** Family members, friends, nurses, aides or paraprofessionals who give direct care to the user in any environment.
- **Teachers:** Educators involved with the user.
- **Treating therapist(s):** Physical therapist, occupational therapist or speech pathologist who assesses the needs of the user, formulates goals and provides or prescribes treatment interventions to meet those goals. Therapists may work with the user at school, at home or in a clinic.

Robbie Shauer (center) tries out a seating system surrounded by team members (from left) physical therapist Linda Cimino, Robbie's mom, occupational therapist Stephanie Welson and rehabilitation technology supplier Faith Safter, P.T.

The treating therapist may not know enough about the various types of currently available equipment to make a recommendation. In this case, the therapist may refer the child to another qualified professional for actual recommendations. The treating therapist must collaborate with the assistive technology assessment team to ensure they have accurate and up-to-date information about the user, including past history, present goals and problems, and the reason for the referral. Some treating therapists have additional expertise in the area of specialized equipment, and can also serve as the child's assistive technology practitioner (see below).

- **Assistive technology practitioner (ATP):** Sometimes called an adaptive equipment specialist, the ATP is usually a physical or occupational therapist who specializes in assessing clients for specialized equipment and can assist the treating therapist in meeting treatment goals through the use of adaptive equipment. In most areas, these professionals can be found in wheelchair clinics or schools for children who are technology-dependent.



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The ATP is a resource for the child, the family and the treating therapist. He or she also acts as team coordinator—arranging for assessment visits and product trials, preparing supportive documentation, ensuring that recommendations reach the proper physician(s) and making sure that all materials needed for funding submissions are completed in a timely fashion. As coordinator, the ATP facilitates all interactions with the rehabilitation technology supplier, arranges for fittings and deliveries, and follows up on any problems that arise during the process.

• **Rehabilitation technology supplier (RTS):** Formerly called an equipment dealer or vendor, sometimes still called a durable medical equipment supplier, this person works for a local company that supplies durable (i.e., not disposable) medical equipment. The RTS has special expertise and experience to assist the clinical team in the hands-on assessment process and is knowledgeable about the types of commercially-available equipment. The RTS will also be knowledgeable about possible custom (individualized) modifications to existing equipment, creating certain types of equipment from raw materials (called fabrication).

The RTS can provide information on prices and funding. He or she should offer the team a menu of choices for discussion, provide equipment for product trials and be available for assessments, interim fittings and delivery. The RTS usually works for a company that can provide support services (i.e., repairs and maintenance) to users.

• **Manufacturer:** The manufacturer is the company that actually makes the piece of equipment.

Manufacturers must follow strict regulations developed and enforced by the Food and Drug Administration (FDA). Some rehabilitation technology suppliers create seating systems "in house," but are rightfully termed "fabricators," not "manufacturers." Some manufacturers sell directly to consumers, but most require that the consumer make purchases through a rehabilitation technology supplier. This allows the manufacturer to be sure the equipment is being supplied appropriately, and that the consumer will have a local source for service and repairs.

• **Manufacturer's representative:** This person may work directly for a manufacturer or be an independent representative for several manufacturers. "Reps" usually serve a specific geographic "territory" and work directly with rehabilitation technology suppliers in their territory—providing equipment for trials, giving presentations about the use of their equipment and troubleshooting when problems arise with the manufacturer or when a consumer has a special need.

The representative has a vested interest in the products they represent. Their incomes are based on the amount of equipment ordered from the company they represent through the rehabilitation technology suppliers in their territory. Representatives

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Our Child Needs a Bath Chair

The TREATING THERAPIST speaks to the FAMILY to discuss their goals for this piece of equipment. The THERAPIST may do a home visit to determine the type of equipment that might work best for the USER in her home environment.

OPTION #1

The *family* plans to pay for the bath chair initially. The case manager at their health insurance company tells them they may submit for reimbursement from the company—*the payer*—after the fact. The *treating therapist* and the *family* look through catalogs from various *distributors* and some *manufacturers* who sell direct. They choose an appropriate chair and place an order. The chair is shipped to the *family* from the *distributor* or *manufacturer*. The *family* and *therapist* read the instructions and learn to use the equipment properly. If any problems arise with the chair, the *family* will have to deal directly with the *distributor/ manufacturer*.

OPTION #2

The *treating therapist* calls an *RTS* who helps the *therapist* and the *family* select a product. The *RTS* may obtain sample bath chairs for the child to try from the *manufacturer* or the local *manufacturer's representative*. The *RTS* provides a price quote and submits it to the *payer* for prior authorization. When the equipment arrives, the *RTS*, or someone from his or her company, will assemble it, deliver it and demonstrate its use. If any problems arise with the chair, the *RTS* will deal with the *manufacturer* on the family's behalf.

OPTION #3

The *treating therapist*, who is not familiar with the full range of available bath equipment, contacts an *ATP* who works at the equipment clinic where the child's previous equipment needs have been evaluated. The *therapist* and *ATP* discuss the child's needs and therapy goals and, with the *family*, select an appropriate chair. The *family* can then order the chair from a *distributor* (See Option #1) or through an *RTS* (See Option #2). To facilitate funding of this purchase, the *ATP* can assist with processing insurance forms and can provide a letter of medical necessity for the *payer*.

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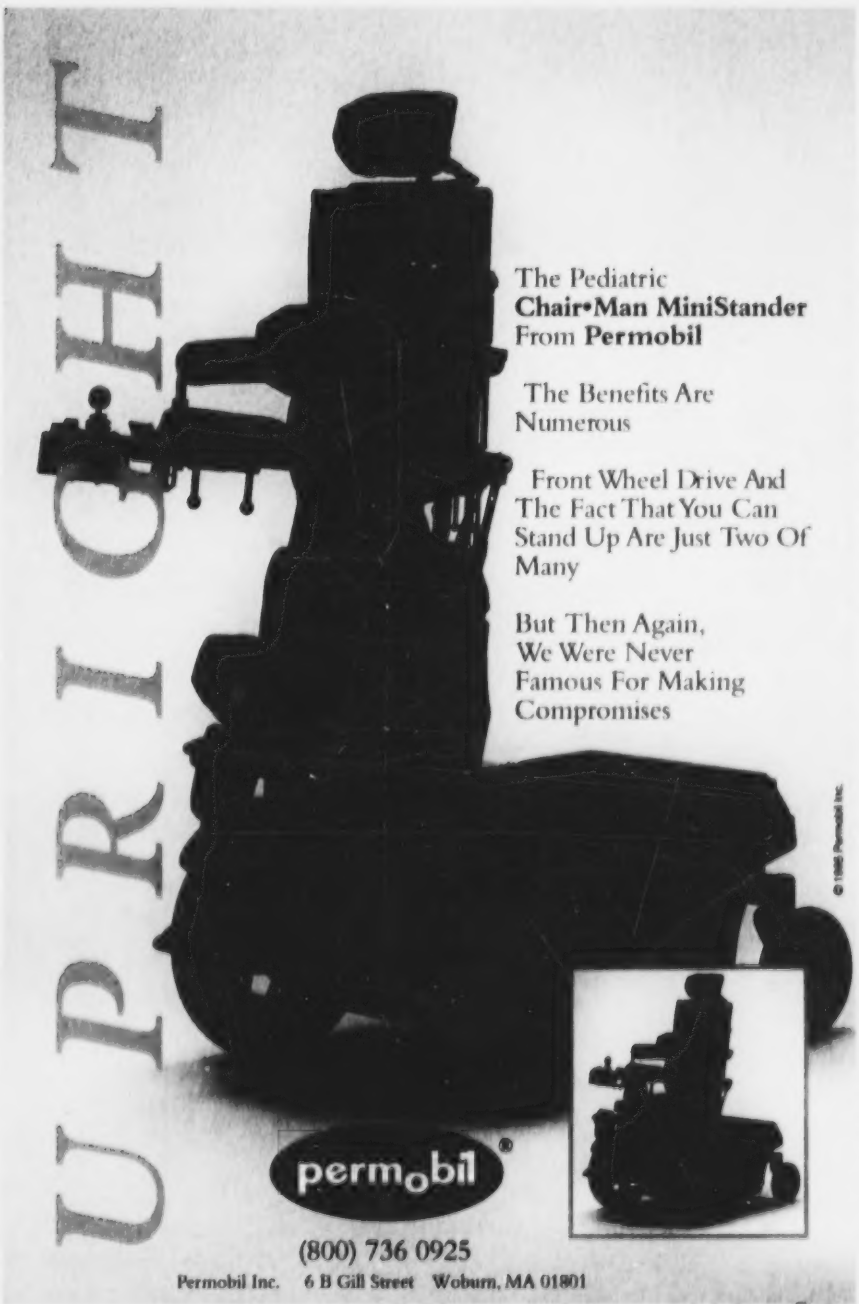
Our Child Needs a Wheelchair and Seating System

The *family* deals with a combination of payers, or funding sources, including private insurance and Medicaid. The private insurance company has a list of preferred providers, but these providers are all home medical equipment suppliers, none of which have an RTS on staff.

The insurance company's case manager gives the *family* permission to seek a supplier outside of their regular network.The *family* asks the *treating therapist* if the child might be a good candidate for a power wheelchair. The *therapist* calls the *ATP* and discusses the issue. The *child* goes to the wheelchair clinic, either with or without the *treating therapist*, for an initial evaluation.

After obtaining all the necessary information about the child's abilities and goals and the environment in which the chair will be used, the *ATP* makes arrangements with the assigned *RTS* or a *manufacturer's representative* to have a power chair delivered to the child's school for a product trial. Once a product decision is made, the *ATP* facilitates its purchase and funding as described in Option #3 in the bath chair example.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may not know about or suggest products from other manufacturers, even if they might be more suitable for an individual user.

• **Distributor:** This person gathers equipment manufactured by many different companies and offers it for sale. They may also manufacture some equipment. Distributors usually can provide a catalog. Consumers may buy directly from the distributors or go through their local RTS. The RTS may charge a higher price for the same equipment to cover the costs for obtaining it from the manufacturer.

• **Payer:** The payer is the source for funding for the equipment—usually a private health insurance carrier or Medicaid (which can be used only after other available funding sources have been exhausted or if a child has no other health insurance).

Some insurance carriers have "preferred providers." To receive full reimbursement, consumers with this type of coverage must obtain equipment from a specific provider on the insurance company's list. However, most insurance companies will make exceptions if listed companies cannot provide the type of equipment being prescribed. **EP**

Adrienne Falk Bergen, P.T. has been a physical therapist for 25 years. She worked for 15 years at Blythedale Children's Hospital in Valhalla, New York. For the last 10 years, she has worked as a rehabilitation technology supplier with Dynamic Medical Equipment in Westbury, New York. Adrienne is a past chairperson of the National Registry of Rehabilitation Technology Suppliers (NRRTS). She lives in Valhalla, New York with her sons, David and Justin, and husband, Barry.

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Finding a Rehabilitation Technology Supplier

Many rehabilitation technology suppliers are skilled in providing specialized wheelchairs, walkers and other mobility devices for children and young adults with disabilities. But how can parents avoid those few suppliers who are incompetent or downright unethical?

Your child's doctors or therapists may refer you to a qualified rehabilitation technology supplier. Parents of children who use similar equipment can be another excellent resource. Local disability service organizations may also be able to make suggestions.

Professional organizations can also make referrals:

• **The National Registry of Rehabilitation Technology Suppliers** (NRRTS) is a nationwide organization of more than 250 members. Members must have demonstrated competence through experience and education. They are also required to sign a code of ethical conduct and obtain recommendations from local health care professionals.
NRRTS, 3223 South Loop 289, Ste 600, Lubbock, TX 79423, (806) 797-7299 (voice), (806) 797-4820 (fax).

• **The MED Group** is a nationwide network of independently-owned-and-operated rehabilitation and home medical equipment retailers and repair centers. The MED group certifies technicians who repair wheelchairs.
The MED Group, 3223 South Loop 289, Ste 600, Lubbock, TX 79423, (800) 477-6272 (voice), (806) 793-6480 (fax).

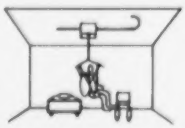
• **RESNA** is a professional organization supporting the use and development of assistive technology. Currently, RESNA is forming a quality assurance program for rehabilitation engineers and other professionals.
RESNA, 1700 N Moore St, Ste 1540, Arlington, VA 22209, (703) 524-6686 (voice), (703) 524-6639 (TTY), (703) 524-6630 (fax).

• **National Association of Medical Equipment Services** (NAMES) represents more than 2,000 home medical equipment and rehabilitation technology suppliers.
NAMES, 625 Slaters Ln, Alexandria, VA 22314-1176, (703) 836-6263 (voice), (703) 836-6730 (fax).

• **The Joint Commission on Accreditation of Health Care Organizations** develops standards and accredits organizations in all areas of health care.
Joint Commission on Accreditation of Health Care Organizations, One Renaissance Blvd, Oakbrook, IL 60181, (708) 916-5800 (voice).

—Dan Lipka

Dan Lipka, M.Ed., is a licensed occupational therapist and an adaptive seating and mobility specialist with Miller's Adaptive Technologies in Akron, Ohio. He is the vice president of NRRTS.



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Circle #39

Powered Mobility?

Making an informed decision

by Phil Reppert

Parents frequently ask whether or not to introduce a powered wheelchair to their child. The question is phrased in many different ways: Will my child still want to walk if she receives a powered wheelchair? Will my child's arms become weaker if he uses a powered wheelchair instead of pushing a manual wheelchair? Will my child become lazy? Is my child too young?

A child's therapist or physician may express a strong opinion for or against powered mobility. Many times, two therapists will have opposing opinions.

There is no single "right" answer to a parent's question about powered mobility. Each child is different. Each family is different. Each home, community, school and job is different. However, by developing mobility goals and a plan of action with a child's therapists, the family can make a more informed decision based on their needs and values.

Sonia Quijano, 16, received her first powered wheelchair when she was 13.

Sonia's story

Sonia Quijano, 16, is a high school student with cerebral palsy. She began receiving ongoing therapeutic services at age five. Each year, her therapists established goals for her to push her manual wheelchair and walk with bracing. But at age 13, Sonia still did not have a useful form of mobility that allowed her to keep up with her peers.

At that time, her therapists decided to spend six months documenting Sonia's ability to use three forms of mobility—walking, manual wheelchair pushing and powered mobility. The goal was to discover the form of mobility that would allow Sonia to move at the same speed and for the same distances as her peers.

After testing her standing and walking ability, it was determined that walking would not meet her daily mobility needs. Standing and walking remained a part of her therapeutic program in order to facilitate her ability to transfer (for example, from chair to toilet) and possibly walk with assistance for short distances.

At the time of her evaluation, Sonia had the ability to push her manual wheelchair slowly. When she attempted to propel her wheelchair quickly, she could maintain the speed for only a short distance. Sonia's therapists established as a goal that she would improve her ability to push her manual wheelchair, increasing speed and distance, moving up and down ramps and maneuvering the chair in tight spaces. Therapists encouraged Sonia and her classroom staff to let Sonia push the chair independently.

Sonia's therapists measured speed and distance before and at the end of the six-month period. There were small improvements in her ability to push the manual wheelchair faster over longer distances. However, she was still being pushed by others, particularly when she had to be somewhere within a specific time period. Sonia continued to lag far behind her classmates when moving to different locations within the school.

After the manual wheelchair training period, Sonia was introduced to a joystick-controlled power wheelchair. Within a few days she was fully independent. Using a fraction of the energy required to push her manual wheelchair, Sonia was able to go anywhere in the school. Her heart rate was significantly lower than when she was pushing her manual wheelchair. Timing the speed at which she traveled specific distances within the school, her therapists found the powered wheelchair to be about three and a half times faster than her manual chair. In the powered chair, Sonia sought out and initiated social contacts, rather than sitting passively in the same place.

After these trial periods, Sonia and her mother agreed with the therapists that a powered chair was the only way for her to move at the same speed and distance as her peers. Her therapists used their documented observations of Sonia's increased independent mobility, along with issues of safety, greater vocational choice and less caregiver supervision and responsibility, to gain approval for the prescription and funding of Sonia's new powered chair.

An informed decision

Here are suggestions for parents to make an informed decision about powered mobility with their child's therapists and other team members:

• *Develop mobility goals and a plan of action with your child's therapists.* Along with your child, list daily activities that are important for your child to perform at home, at school and in the community. Home goals may be to travel independently several city blocks to a local playground or grocery store, or to move around the backyard while playing with siblings.

Go to your child's school and observe the daily activities your child participates in with peers. A school goal may be for the child to move independently at the same speed and for the same distances as classmates during all school activities.

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Together with your child and team members, develop a plan of action to determine the method(s) of mobility that may allow your child to meet these goals. Should an intense period of physical therapy concentrate on a child's walking ability? Should an effort be made to develop the child's pushing skills in a manual wheelchair? Should the child immediately begin training with a powered wheelchair? Should he or she develop walking skills for short distances and learn to use a powered wheelchair for activities that involve traveling longer distances?

Whatever the plan of action, set time limits with therapists to assess whether or not your child is developing the skills required to meet the mobility goals. If a child is not benefiting from the current plan of action, valuable time can be lost.

• *Have your child try a powered wheelchair.* Have your therapist help you and your child obtain a powered wheelchair for trial use. Many times, the advantages and disadvantages of a powered wheelchair are not recognized until the child actually tries the device. Having a child try using a powered wheelchair in his natural environment—such as school—can provide parents, therapists and educators with valuable information about his ability to use the chair safely and responsibly.

• *Make your therapists accountable for the information they are providing to you.* Your therapist may have a very strong opinion about whether or not your child should use a powered wheelchair. A therapist may suggest that if a child begins to use a motorized wheelchair, he will lose all desire to walk. Likewise, another therapist may indicate that if a child can move independently in a powered wheelchair, his desire to move and walk will increase. Ask therapists to provide you with documented cases or research that supports their opinions.

• *Talk to other parents and children who have dealt with the same questions about powered mobility.* Sometimes, the best resource is other parents. Ask your therapist to put you in touch with other parents who have dealt with similar questions and decisions. **EP**

Phil Reppert is a physical therapist working with children and young adults in the New York City public schools.

A Larger View of the World

Our nine-year-old son Danny was born prematurely with complications arising from a group B strep infection. Oxygen deprivation resulted in permanent brain damage that left him unable to walk independently, unable to sit for long periods and only able to use his right arm and hand for functional tasks. He has some visual-perceptual difficulty, but above-average intelligence.

When Danny was three, we began to notice that his lack of independent mobility was adversely affecting his development because he was not able to see and experience the world like a child who is mobile. His view was from his highchair or the floor.

Although Danny's occupational therapist recommended a power wheelchair, we were reluctant because we felt he could make progress with a walker. We wanted to "force" him to go as far as he could, hoping he would become a "walker."

We agonized over this decision, but finally ordered his first chair—on his fourth birthday—based on three factors. First, Danny was getting bigger and more difficult to handle at home and at the regular nursery school he was attending. Second, we wanted to make sure he developed at an appropriate rate. Third, his physical therapist told us that "sometimes it is better to have a happy wheelchair user than an unhappy walker."

Now a third-grader, Danny has been in a regular class at our neighborhood school since kindergarten, except for first grade, where he was placed in a self-contained learning disabilities class where he made little progress. He is now pulled out of class for physical and occupational therapy sessions and receives individual and small-group tutoring in reading and math.

Being in the regular class has been a very positive experience for Danny, his teachers and the other children. We have seen him grow in independence, class participation and maturity. And he has lots of friends without disabilities from school, church and our neighborhood. He loves to play cops and robbers at recess and is able to keep up with the other kids in his power wheelchair.

Safety was a big concern for us. But we feel comfortable letting him zoom around the neighborhood with his seven-year-old sister. He can even use his chair to explore the woods behind our home.

Danny's full inclusion in the community would have been difficult without independent power mobility.

—Dan and Margie Wright
Hudson, Ohio

Danny won the "Most Patriotic Float" award at a neighborhood Fourth of July parade last year.

Controls for Power Wheelchairs

Choosing the most appropriate control

by Peggy Barker

Power mobility can be considered for many children even if they cannot use a hand-controlled joystick. A child's physical abilities can be matched to the characteristics of available controls (See sidebar: "Control Options for Power Wheelchairs," page 36). Before beginning this process, it is important that the child is securely and comfortably positioned. (See "Proper Seating and Positioning," February 1995).

Once positioned, the child should be able to work with each potentially useful control, with supervision, until the evaluator determines whether that control is effective. Proportional controls should be considered first because they provide fine control. Switch arrays should be considered next. A single switch with scanning should be considered as a last resort; scanning systems require extra time because the user must wait for all possible activation choices to be scanned before he or she can choose a function.

For many children, a two- or three-hour trial will not be sufficient. It may require several weeks to become accustomed to operating the control while the chair is moving. A rental program that includes power wheelchairs of different sizes, with various positioning components and a variety of control options, can be used to give a child more time to practice with the control and to experience power mobility. The rental program should give the child two weeks to three months to work with the equipment. A rental can also allow the child's family and teachers to evaluate the chair at school and home. A follow-up evaluation is needed to determine whether the child can learn to operate the power mobility system safely, and if so, to justify its purchase for funding agencies.

A child's ability to use a power wheelchair should continue to be re-evaluated on a regular basis. As children grow and mature, their physical control and potential to safely and effectively operate a power wheelchair usually improves. **EP**

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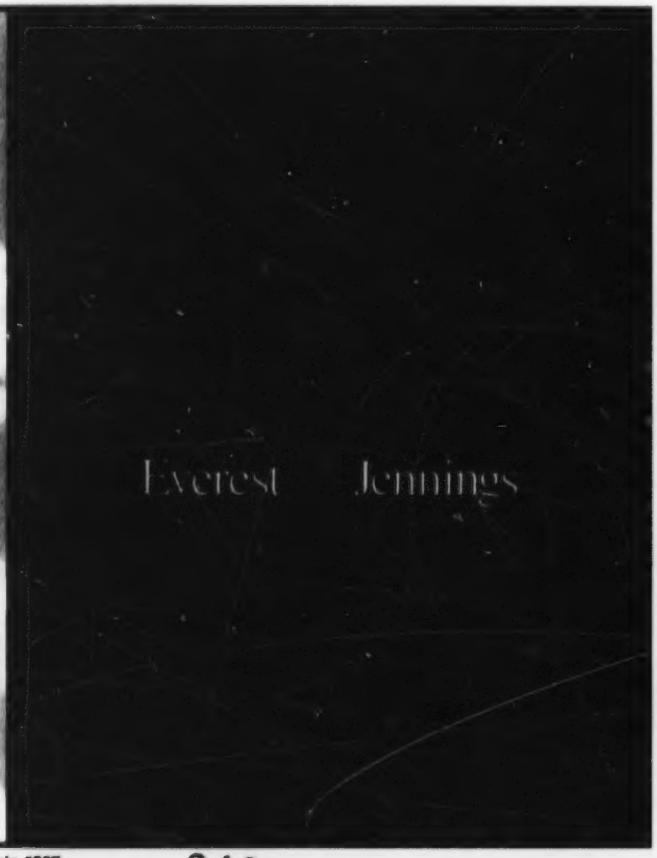
They've headed safaris in their neighborhood park, and pondered the panthers and pythons, then probed along the surface of Mars in their trusty all-terrain vehicles. They've recovered the last of the golden keys while their computer proclaims them heirs to the realm. Kid Power™ is for kids making tracks. A child's tool, like a child's toy must be durable and adaptable, allowing them the freedom and range to explore their environment creatively and independently. Kid Power™ is tough and reliable with a unique styling that adjusts to your child's changing needs. Kid Power™ is easy to program, with precision controls, accessible battery boxes, controlled tracking, a rugged steel frame and a host of options that allow kids to assert their individuality and lifestyle.



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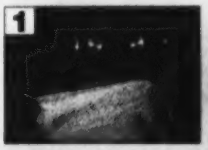
Circle #156

Control Options for Power Wheelchairs

• **Proportional controls** (used for incremental control of direction and speed) include hand-, head- or foot-controlled joysticks, or "short-throw" joysticks that require less movement to reach the chair's maximum speed.

Proportional head-controlled joystick.

• **Non-proportional controls** (used to just turn a function, like direction or a certain speed, on or off) include contact switches activated by a press or a touch, proximity switches activated by the user's physical closeness, puff-sip switches or a single switch with scanning of all directions that may be used to activate all the functions of the chair.



#1: Contact switches: an array of three disc switches on an adjustable mounting bracket. #2: Scanning array: an array of scanning lights is used to select the direction the wheelchair will move. A single switch is used to stop the scanning at the chosen function. #3: Proximity switches: three switches imbedded in a headrest are activated by the user moving his or her head closer to the headrest.

Peggy Barker, M.S., is a rehabilitation engineer working as an independent consultant. She previously was the communication/control service chief at Packard Children's Hospital, Stanford Rehabilitation Engineering Center in Palo Alto, California.

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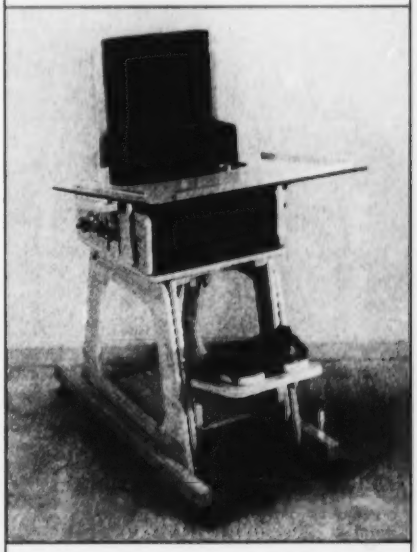

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The Art of Manual Wheelchair Maintenance

by Mary Angelico

Like changing the oil in your car, manual wheelchair maintenance can be relatively easy and inexpensive. Poor wheelchair maintenance can lead to expensive repairs, discomfort and a loss of function.

In many cases, older children can learn to be responsible for their chairs by doing routine chair care and scheduling professional maintenance appointments.

Keeping the wheelchair as clean as possible is probably the easiest and most effective way to prevent wheelchair breakdown. Routine care includes:

- Wiping down spills as soon as possible.
- Cleaning out cracks and crevices where crumbs and dust collect.
- Washing and air drying cushion covers, on a weekly basis if necessary.

The following are guidelines for maintenance to be done every two months. This schedule may vary depending on ways the wheelchair is used. Develop the best maintenance schedule for your needs with your rehabilitation technology supplier (RTS).

Seating system

If your cushion is made from Naugahyde, which is not 100 percent waterproof, it can be wiped down with a sponge and warm, soapy water (using a mild dish detergent) and then dried immediately.

If your cushion has a removable cover made from nylon or Lycra, follow the manufacturer's washing instructions precisely, or wash the cover using Woolite and cold water; then hang it to dry. With the cover removed, wipe the cushion with a damp rag without soap.

If your cushion's cover is not removable, you can clean it with warm, soapy water and a soft-bristled brush. Use as little water as possible, and soak up excess water with a dry cloth. Air dry or use a cool blow dryer only. Once

continued on page 40

Kyle's New Bike

Even though Kyle Romano lost both arms and both legs to amputation before the age of two, he never lost his enthusiasm for life and his desire for independence. His family made sure of that.

Surgeons amputated his arms above the elbows and took two thirds of both legs because a rare disease, meningococcemia, damaged his circulation, caused gangrene, and almost took his life.

Now an energetic seven-year-old, Kyle gets around school in his power chair, rides horses and has been involved in Little League baseball. But there was one thing the Tampa, Florida native always wanted to do but never could—ride a bicycle with his friends.

"I've wanted it since I was four," Kyle says.

Kyle Romano tries out his new bike. With him are younger brother Kent and parents Kris and David.

He got his wish recently when 11 mechanical engineering students at the University of South Florida (USF) presented him with a specially-designed tricycle he can power and steer on his own.

The tricycle, with two wheels in front and one in the back, was designed and built by the USF students as a class project. It took eight months to complete.

Kyle uses the stub of his right arm to steer the vehicle and the stub of his left arm to shift and brake. He powers his bike by pushing his chest forward against a padded bar and then back. Both motions make the bike move.

"We created a drive arrangement where you convert the rocking motion into a forward rotation of the rear wheel," USF professor Stuart Wilkinson explains. "It's unique."

USF student Brian Corces, who worked on the project, will work with Kyle as part of an independent study program to make any adjustments to the bike, that is, if Kyle stays off it long enough. According to his mother, Kris, the energetic boy rides it almost every day with his friends.

"His friends think it's great that he can power it himself," she says. "They help him when he gets into jams. They're very supportive."

She also has noticed a change in his self-esteem and spirit.

"He has a new feeling of independence," she said. "Our only trouble is keeping him off of the bike, especially when he has homework... just like any other child."

—Ron Faig
University of South Florida, Tampa

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PRODUCT NEWS

Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use. **Circle # 209**

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A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.

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Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.

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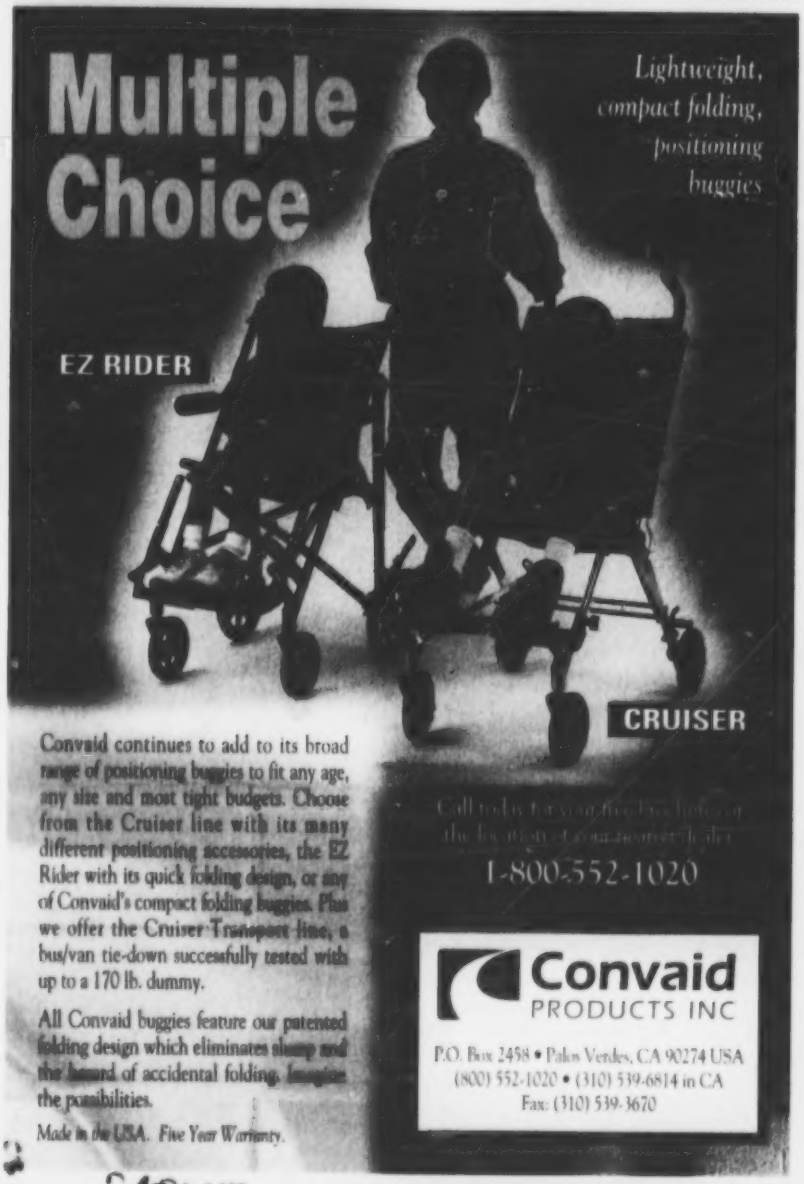
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Circle #150

continued from page 38

dry, the cushion can be brushed to soften it up.

The seat pan—the metal or plastic piece that the cushion rests on—can be safely cleaned with a sponge and warm, soapy water. Don't use steel wool pads; they will scratch the surface.

Frame

The frame of your wheelchair includes the seat rails, the upright cranes and if present, cross braces. Clean these parts with a damp cloth and warm, soapy water. Do not use an abrasive cleanser or steel wool because they will scratch the paint. Grease spots may be removed with a spray cleaner, such as Fantastic or Formula 409. Touch-up paint may be available through your RTS.

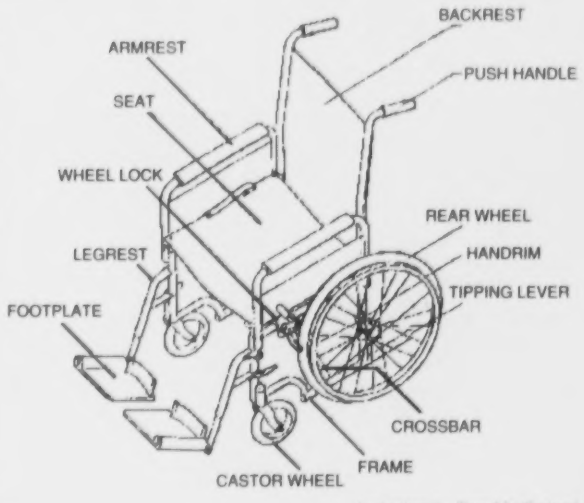

Illustration by Sam MacFarland

Wheels

Wheel maintenance includes the tires of the rear wheels, spokes, axles, wheel locks and casters (the front wheels).

- Tires are either solid rubber or filled with air (pneumatic). Check solid tires for wear and tightness to the wheel (there should not be any slack). Worn tires should be replaced before the inner material is exposed. Check pneumatic tires for pressure and for tread wear. If the treads appear less than one centimeter deep, they should be replaced.
- Wheel alignment can be checked by allowing the wheels to rotate freely without touching the floor. (You can check one wheel at a time by turning the chair on its side). If the wheel wobbles when you spin it, it is not properly aligned and requires maintenance by your RTS.
- Check the wheel locks when you check alignment. Engage the locking mechanism and try to turn the wheel. If the wheel moves at all, either the lock or the tire pressure needs adjustment. Ask your RTS for assistance.

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• To clean dirt and grime from quick release wheels, remove the wheel and scrub the axle with a steel wool pad. Wipe off excess soap and grime with a wet rag, then dry the axle. Re-lubricate the axle using household oil, such as 3-in-1, available at most hardware stores. Clean the hole the axle fits in by pulling a rag through it several times, and re-lubricate it with household oil.

• The wheel spokes need to be evenly tightened for proper tire alignment. If a spoke is loose, you can use a spoke tightener to secure it. Both over-tightened and under-tightened spokes affect the ride. If you are uncertain doing this, ask your RTS to do it.

• Casters tend to pick up lint, thread and other debris. Remove this debris from the caster forks and clean the axles in the same manner as the rear wheel axles. Instructions on caster removal are in the wheelchair booklet supplied by the manufacturer.

Supports

Position and condition of leg rests, footrests and armrests are critical to comfort and function for the user. If leg rests are removable, check the locking mechanism to see that it works smoothly and easily. After cleaning the entire leg rest and footrest assembly, use household oil to re-lubricate the hinges on the calf pad, footrest and knee hinges. Clean the armrests and, if necessary, the posts they slide into. If there is excessive motion in the armrest and an obvious loose screw, tighten it. If the problems persist, check with your RTS.

Wheelchair tune-ups

Wheelchairs and their seating systems should have a tune-up—usually called a clean, lube and overhaul—every six months by your RTS. Tune-ups include replacement of bearings, a complete cleaning, lubrication of all moving parts and a check to make sure all screws are tightened.

Tune-up costs range from $50-$100. The cost may include pick-up and delivery of the chair and, if possible, the use of a loaner chair.

Many services may be covered in the chair's warranty. Before paying for any service, be sure you are familiar with your warranty's inclusions and limits. **EP**

Mary Angelico, P.T. is an assistive technology practitioner in physical therapy in private practice. She has worked for the past nine years in the Chicago area at LaRabida Children's Hospital and the Assistive Technology Unit, Institute on Disability and Human Development at the University of Illinois.

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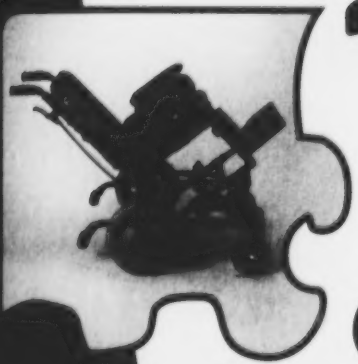

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The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dysphagia.

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Circle # 211

Special Needs in the Lunchroom

Modifying school meals for students with special eating needs

by Gloria Frolek Clark

Tacos, grapes, carrot sticks, an iced cinnamon roll and milk. Sounds like a typical school lunch, right? Most children have two options—eat hot lunch or bring lunch from home. But what are the options for children who choke on any foods except baby food, easily aspirate liquids (swallow liquids into the lungs), need low-calorie meals due to medical disorders, are allergic to certain foods, or are unable to chew food?

A "typical" lunch could be life-threatening to children with special needs.

Consider Nicki, a seven-year-old girl with head injuries, who cannot chew food and needs it blended to the thickness of pudding. Nicki refuses to eat most vegetables and fruits. Her teacher and parents have noticed that if they mix her food with mashed potatoes, she will eat more. This is crucial because she has lost five pounds in the last year and is now below the fifth percentile when her height-to-weight proportion is graphed on a growth chart.

Liquids also run down Nicki's throat too fast and cause her to choke. The school occupational therapist has recommended that the liquids be thickened using baby food cereal, yogurt or blended fruit, such as applesauce.

How can Nicki's school lunch be modified to make it safer and provide her with the nutrition she needs?

School requirements

The Rehabilitation Act of 1973 required recipients of federal funds to make their programs and activities accessible to all individuals with disabilities. Section 504 of the act incorporated new regulations for school meal programs into the Child Nutrition Program Regulations of 1988, commonly known as the breakfast and hot lunch program. These regulations require schools to modify or make substitutions in meals at no extra charge for students who meet the definition of having a disability and whose disability restricts their diet. A person meets this definition if he or she has a physical or mental impairment which "substantially limits one or more major life activities," has a history of having such an impairment or is believed to have such an impairment.

With help from occupational therapist Gloria Frolek Clark, preschooler Derek Harrison practices drinking from a cup.

Since the Child Nutrition Program Regulations are monitored through the U.S. Department of Agriculture (USDA) rather than the U.S. Department of Education, families and professionals who care for children with special needs are often not aware these regulations exist.

A variety of modifications and substitutions may be necessary to allow a student to consume the meals offered to students without special needs. Some students with gastrostomy tubes may require a liquid formula, while other students may require modifications such as:

- Substitutions of menu items to accommodate such dietary restrictions as allergies, or foods that don't purée well.
- Recipe modification to provide foods that are low or high in certain elements such as fat, sugar, fiber or protein.
- Texture modifications such as thickening liquids, or grinding or chopping foods.
- Other modifications in food characteristics such as temperature, portion size and nutrient composition.

It is imperative that nutritional value be considered when making any modifications to the meal. For example, if certain foods are prohibited, substituted foods should be similar in nutrient content.

Updated instructions issued in October 1994 by the USDA provide guidance to schools participating in breakfast and hot lunch programs. If a school is not a participant in this federal program, they may still be obligated to make modifications and substitutions based on the Individual with Disabilities Education Act (IDEA). IDEA may require school food authorities to provide meals outside of the regular meal schedule or to provide services that are not usually required by the Child Nutrition Program.

Feeding and nutrition goals

Food modifications can be listed on:

- An Individual Education Plan (IEP).
- A Student Health Care Plan attached to the IEP.
- A goals-and-objectives plan related strictly to feeding and nutrition.

Even students who do not qualify for special education services are eligible for special food services as long as they meet the criteria for hav-

ing a disability under the Rehabilitation Act of 1973.

In most cases, the school will require a physician's statement regarding the child's disability and related dietary restrictions. The school must determine if this student meets the regulatory criteria of the Rehabilitation Act of 1973, and is only obligated to provide those substitutions and modifications deemed necessary by the physician.

Changing the texture of the meal—by such processes as blending, puréeing or chopping—does not require a physician's order, though it is helpful information for the school food service.

Inclusion

In addition to meal modifications, the regulations state that food services be provided in the most integrated setting appropriate to the special needs of the student. Unfortunately, students with special feeding needs often are not integrated into the lunchroom to the maximum extent possible.

A team effort

A team approach is critical for a child with feeding and nutrition problems. This approach has made a difference for Nicki.

Nicki has been followed closely by a nutritionist since her parents and occupational therapist became concerned about her weight loss. Her height and weight are being closely monitored by the school nurse and her regular physician. The nutritionist also discussed the need for supplemental vitamins and minerals because of the anticonvulsant medication she takes daily. The educational team has met to discuss the school food modifications that were needed for Nicki. The family, teacher, occupational therapist and nutritionist provided input that was used to develop a plan. The physician had been kept informed of Nicki's needs and difficulties with the school lunch.

As a result of this team effort, specially prepared meals are now available each day for Nicki's lunch. Nicki's teacher keeps in constant contact with the school lunch supervisor regarding the modifications and how they are working for Nicki.

For more information about school food regulations, contact the food and nutrition service staff at your state Department of Education, or your local school district administrator. **EP**

Occupational therapist Gloria Frolek Clark, OTR/L FAOTA works for the Heartland Area Education Agency in Johnston, Iowa, and is in private practice. She chairs the School System Special Interest Section of the American Occupational Therapy Association. Gloria lives with her husband and three children in Ankeny, Iowa.

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WHAT'S HAPPENING

Violinist Itzhak Perlman hosts PEOPLE IN MOTION: AN INNOVATION MINISERIES. The series' three episodes—"Ways to Move," "Ready to Live" and "Redesigning the Human Machine"— explore dramatic advances in technology, medicine and attitudes that are changing the lives of people with disabilities. Ed Roberts, disabilities activist and founder of the Center for Independent Living; Marilyn Hamilton, co-founder of the Quickie wheelchair company and Ed Tessier, a former congressional candidate from California who is quadriplegic, are some of the remarkable people featured.

PEOPLE IN MOTION premieres March 31 at 9 p.m. on PBS (check local listings). A free viewer's guide is available. Write to PEOPLE IN MOTION, P.O. Box 245, Little Falls, NJ 07424-0245.

Twelve-year-old Carl Burnett of Cape Elizabeth, Maine enjoys "mono-skiing" at the United Airlines Ski Spectacular, held in December in Breckenridge, Colorado. The Spectacular, sponsored by National Handicapped Sports (NHS), attracted skiers with disabilities from all over the country. The week-long event included ski instruction, racing clinics, elite training camps and a giant slalom competition. (Photo: Bruce Barthel)

Calling Young Playwrights

The Very Special Arts 1995 Young Playwrights Program has issued a call for scripts written by 12- to 18-year-old playwrights. Scripts must deal with some aspect of disability and must be postmarked by April 14, 1995. The winner of the competition will travel to Washington, DC to see his or her play produced at the John F. Kennedy Center for the Performing Arts.

Very Special Arts is an international organization providing programs in creative writing, dance, drama, music and the visual arts for people with disabilities, especially children and youth. For more information about Very Special Arts, or for details about the 1995 Young Playwrights Program, contact Very Special Arts, The John F. Kennedy Center for the Performing Arts, Education Office, Washington, DC 20566, (202) 628-2800 (voice), (202) 737-0645 (TTY).

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Circle #59

ASK THE DOCTOR

by David Hirsch, M.D.

Infantile Spasms

Q At about five months of age, our son developed a type of seizure disorder called infantile spasms. Prior to this time his development was normal. He has brief myoclonic spasms lasting a few seconds but occurring many times each day. After a bout of these spasms, he is irritable, then he seems to become drowsy. He is now one year old and is delayed in all areas. He has been on a number of different anticonvulsants including Valproic acid, benzodiazepine, and ACTH. Nothing has seemed to work very well for any period of time. Recently, I heard about a fairly new medication called "Sabril" that has helped in the treatment of infantile spasms. Is this medication worth trying?

A Infantile spasms, sometimes called West syndrome, is a type of seizure disorder with a clinical pattern that most commonly consists of frequent myoclonic spasms (unpredictable contractions of one or more muscle groups) and a unique electroencephalographic (EEG) pattern called "hypsarrhythmia." As in your son's case, most children with infantile spasms develop this condition in the first year of life. Other terms for infantile spasms that describe some other types of seizures associated with it are "lightening" or "jackknife" convulsions.

Unfortunately, infantile spasms are non-responsive to many of the more conventional anticonvulsant medications. ACTH is a hormone that stimulates the release of cortisone. It has been successful in controlling infantile spasms at least for a while, but it has not been shown conclusively to improve the long-term outcome of this disorder.

Vigabatrin, sometimes called Sabril in Europe, is a newer anticonvulsant that has shown some promise in the treatment of infantile spasms and other complicated seizure disorders. This medication is now being studied and may become available in the U.S. within a year. It certainly would be worth trying. Continue to work with your son's pediatrician and pediatric neurologist. More information on this medication and other newer treatments for various forms of epilepsy can be obtained from the Epilepsy Foundation of America (4351 Garden City Dr., Landover, MD 20785-2267; 800/332-1000, voice; 800/332-2070, TTY), the American Epilepsy Society (638 Prospect Ave., Hartford, CT 06105-4298; 203/586-7505, voice) or Epilepsy Canada (1470 Peel St., Ste. 745, Montreal, PQ H3A 1T1, 514/845-7855, voice). EP

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch mentions specific products or medications only to illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146-5006; (617) 730-8742 (fax).

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Circle #182

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Choosing A Summer Camp

Camp Sky Ranch, Blowing Rock, NC.

Summer camp can be a growing experience for a child and a chance for parents to gain some much-needed respite. Some see summer programs as a way to extend the school year by choosing camps that continue education and therapy goals. Others find the summer a perfect time for their child to get to know other children with and without disabilities.

Where can a child with a disability go to camp?

Possible information resources include:

- Parent organizations, especially those affiliated with a national disability organization;
- Professionals;
- Social service agencies, rehabilitation centers, clinical facilities, or recreational programs;
- Local Parent Training and Information Centers (see *Exceptional Parent's 1995 Resource Guide* for a state-by-state listing);
- Local newspapers (Sunday magazine section) and community parents' newspapers often list camps, camp-referral services and camp fairs;
- Local religious associations, fraternal associations, community organizations and scouting groups, and
- Camp guides which may be available at public libraries. Two usefull guides are:

Peterson's Summer Opportunities for Kids and Teenagers, 1995 edition; lists camps and other summer programs for children of all abilities; also available

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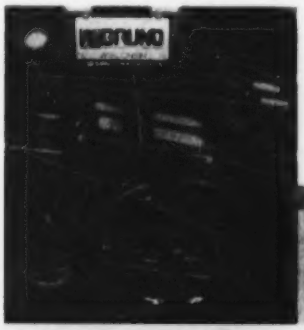

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Circle # 212

That's Steve on the left. He wasn't always this happy and self-assured. Some days he would hit himself thousands of times. His injuries ranged in severity from a bloody nose to a cauliflower ear. His ability to learn and understand himself was affected by his autistic behaviors.

When Steve was 15 years old, his parents enrolled him in Heartspring's residential school. Our interdisciplinary team approach focused a wide spectrum of knowledge on his behavior, combining the efforts of a special education teacher, psychologist, speech therapist, case manager, and of course, Steve's parents. His team determined that his inability to communicate his wants and needs contributed to his frustrations and his inappropriate behaviors, so that's where his plan began.

To address Steve's challenges, a comprehensive program, including behavior management and appropriate alternative ways to communicate, was implemented in his classroom, apartment, and outings in the community.

Steve's life is very different now. He's learned to communicate his needs, and his pattern of hitting himself has been reduced to ten "light taps" a day. Now he can concentrate on other skills. Between working his part-time jobs with his job coach, participating in other learning activities, and doing things with his friends, Steve probably won't have time to self-destruct today.

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Circle #3

What Abby Did On Her Summer Vacation

Kids and summer camp is as much an American institution as Mom and Apple Pie. However, parents of children with disabilities discover that finding a camp suited to their child's special needs is not easy. My search for a summer camp for my 13-year-old daughter, Abby, taught me a great deal about parent advocacy.

Diagnosed with spastic triplegia, Abby arrived from Korea at age eight as one of my 10 adopted children. Although mainstreamed in regular classes in middle school, Abby's wheelchair, her school work and her own demand for achievement created difficulties in making friends. Her chances to make friends were also limited because she traveled alone to school in a special van. Abby desperately needed to learn how to make friends and have fun in a relaxed atmosphere. Camp seemed to be an ideal solution.

Abby Peck attended two one-week sessions at Eagle's Nest summer camp last year: "I did everything the other kids did, and my chair was just no big deal."

To begin my search, I checked with our state special needs coordinator who did a computerized camp search for me. I spoke with people at the regional office of developmental disabilities for referrals. I talked with people on the child study team at school. Our local Cerebral Palsy Association made suggestions. Virtually everyone I spoke to understood the problem and tried to be helpful, but they only referred me to someone else. In the end, I had one solid recommendation—a camp for children with disabilities which I felt was unsuited to Abby's needs.

Abby and I changed tactics. We established a new list of requirements: reasonable accessibility, a relatively flat terrain, a swimming program, a low camper-to-counselor ratio and a pro-

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gram with an emphasis on individual growth and success. I contacted camps in New Jersey and others within two hours of home.

I was straightforward and open. I talked about "accessibility" as a physical reality and a commitment from the staff. I described Abby, her personal independence in self-care and her physical needs in realistic terms.

Amazingly, our decision was made with ease. The Episcopal Diocese of Newark, of which our own church is a part, has run the Eagle's Nest summer camp for many years. Brad Moore, the diocesan youth director, listened to my well-rehearsed "litany" on accessibility and chuckled. "Sure, she can come," he said. "Just be sure you sign up Alee, too!" The thought that Alee, my 12-year-old sixth grader who also has cerebral palsy, might enjoy camp, too, had never seriously crossed my mind in my one-track quest to provide for Abby.

The staff at Eagle's Nest was well-prepared for Abby. Several counselors-in-training volunteered to help her meet the day-to-day physical challenge of platform tent camping. Some were more successful than others. The administration firmly believed that they could meet Abby's needs and that a camping experience for my daughter could be achieved both safely and realistically.

Abby attended two one-week camp sessions last summer. At the end of the first week, I met her at the bus. Three big, strapping teenagers lifted her off the bus and planted her in my car as she giggled in exhaustion and joy. On the way home, she stretched and sighed in contentment. "You know what, Mom?" she asked. "For the first time ever in my whole life, I feel like a regular, normal kid. I did everything the other kids did, and my chair was just no big deal." I wept quietly for her joy.

—Cynthia V.N. Peck

Cindy Peck is a single adoptive parent of 10 children aged 13-25. She is an English teacher and a partner in Seedlings, a licensed New Jersey adoption agency. She is also the editor/publisher of Roots & Wings, a national adoption magazine. For information and a free sample issue, write to Roots & Wings, P.O. Box 638, Chester, NJ 07930. The Internet e-mail address is Rootswings@aol.com.

Choosing A Summer Camp

Camp Courageous of Iowa, Monticello, IA.

at bookstores and through Peterson's, Customer Service, P.O. Box 2123, Princeton, NJ 08543-2123, (800) 338-3282 (voice), (609) 452-0066 (fax).

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Circle #60

Choosing A Summer Camp

Camp Courageous of Iowa, Monticello, IA.

includes camps for children with disabilities; offers tips on questions to ask camp directors, what to pack, combating homesickness and financial assistance; also available through ACA, 5000 State Road 67 North, Martinsville, IN 46151-7902, (800) 428-2267 (voice), (317) 342-2065 (fax).

"Special" or "Regular"?

A "regular" camp will introduce children to peers without disabilities as well as to peers with disabilities different from their own. A special needs camp is more likely to have the equipment, staff and adaptations needed for all campers to participate in activities. In addition, a special needs camp will provide a child more opportunities to share feelings, thoughts and stories of living with a disability.

Expectations

After compiling a list of possible camps, create a list of expectations (parents' and child's) of what the camp will provide. Should it be a fun vacation and/or a time to enhance skills? What do the parents want their child to gain from the experience—friends? increased confidence? a new understanding of the world around them? What are the child's abilities and interests, and how will each of these affect the experience?

When these goals have been determined, a list of questions will help narrow the field of possibilities. Through this list, parents will be able to get a good idea of how the camp will provide for their child. Directly asking "How will you achieve this?" will help to prepare everyone involved. Some topics that may be covered include:

- Camp objectives;
- Health and medical considerations;
- Staff-to-camper ratios;
- Preparedness of staff to deal with emergencies;
- Physical terrain and accessibility of the camp; and
- References: Speaking with other parents and children with disabilities who have attended the camp will give you and your child a more personal view of the camp's potential.

Camp Courageous of Iowa, Monticello, IA.

Visiting the camp will let you make sure that the layout and surroundings meet your expectations and needs.

Once all necessary arrangements have been made, summer camp can truly become a time for special memories.

—Jennifer M. Koerber

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HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

A New Insurance Plan for Individuals Considered "High Risk"

Q My 17-year-old daughter has Down syndrome. I previously worked for a large company and was able to provide her with the best of health care. Now I am self-employed and have no health insurance for her.

My daughter is a healthy teenager. She loves camping, swimming and many other activities that make me nervous. However, I can't restrict her activities just because she lacks adequate health insurance.

Because of her diagnosis, health insurance is extremely expensive. Several insurance companies have said that she is in a high-risk category and prone to having accidents. I can't find an affordable policy.

J.D., Ohio

A This issue needs to be dealt with on a national basis. Hopefully, it will be a major goal of Congress. To help persuade Congress of the importance of this issue, it is essential to write to your legislators about your difficulties in obtaining insurance.

In the meantime, The Arc, a national organization on mental retardation, is in the process of establishing a health insurance program that may meet your daughter's needs. "The Arc Group Major Medical Insurance Plan" has been specifically designed to meet the needs of children and adults with Down syndrome and other disabilities, ages 10 to 65.

According to an Arc representative, the policy represents "the only affordable commercial plan that we are aware of in the market today that does not automatically preclude people with mental retardation."

It's important to be aware, however, that this insurance plan is still in the process of development. The information we have is preliminary; specific policy rules may change as final details are developed. In addition, while the program does not automatically exclude applicants with Down syndrome, mental retardation or other disabilities, there is no guarantee of acceptance. Each applicant will be evaluated individually.

Two plans

The Arc will offer a "Comprehensive Plan" and an "Economy Plan." Both plans have an individual lifetime limit of $1 million. Each plan offers three different deductibles, ranging from $300 to $1,000 per year.

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Once you have paid the year's deductible, the Comprehensive Plan will pay 80 percent of the next $5000 of covered expenses. After that, the Comprehensive Plan will pay 100 percent of covered expenses based on "reasonable and customary" charges.

The Economy Plan will pay 70 percent of the next $10,000 of covered expenses, after the deductible has been met. After that, the Economy Plan will pay 100 percent of covered expenses based on "reasonable and customary" charges.

Coverage

According to the current proposal, both plans will provide coverage for hospitalizations, treatment of mental illness, x-rays, anesthesia, doctors' bills, rental of certain types of medical equipment, ambulance services and laboratory tests. Other medical equipment or services may be covered as well. In addition, there are specific rules and limits for each of these services, and certain treatments or services are excluded.

Availability

The insurance program will be available to members of The Arc and their families, ages 10 to 65. Unfortunately, The Arc has not yet been able to establish a health insurance policy for children with disabilities under the age of 10, or for adults over 65.

For more information about The Arc Group Major Medical Insurance Plan, write to The Arc's insurance administrator, the Albert H. Wohlers Company, 1440 N. North West Highway, Park Ridge, Illinois 60068-1400, (800) 323-2106 (voice). They will send information as soon as policy booklets are available.

For more information about The Arc itself, or to locate the nearest Arc chapter, call The Arc's national office, (800) 433-5255 (voice) or (817) 277-0553 (TTY). **EP**

EDITOR'S NOTE: Some states have established state-run health insurance policies for residents who have been unable to obtain private coverage. To find out if your state offers this type of program, contact the Parent Training and Information Center (PTI) in your state. A complete listing of PTI programs can be found in EXCEPTIONAL PARENT'S 1995 RESOURCE GUIDE (January 1995), or the National Parent Network on Disabilities (703/684-6763, V/TTY) can direct you to the nearest PTI.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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Circle #101

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A New Perspective on Development

by Louie Mauro

(Top) Donna and Louie Mauro with (from left) children David, 2, and Alex, 5.

Playing with Daddy: David (left) and Alex enjoy a game of "tickle."

When our first child, Alex, was born in 1989, we were armed with an arsenal of child development materials. Books outlining the first years of life, magazines charting the month-by-month progression of the typical infant. We poured over the texts in eager anticipation of each exciting milestone. Each author was careful to explain that every child develops at a different pace, that we should not place too much emphasis on the rather arbitrary averages outlined in the books. Good advice, we thought, as we eagerly charted our son's development to see how he stacked up against the "average" child.

Months passed, and an obvious truth became apparent—our son was exceptional, a prodigy, gifted beyond compare. Although he wasn't yet solving math problems or playing the violin, the way he dropped his rubber ball into Tupperware containers was incredible to behold.

Our pride swelled with each new accomplishment. Alex began crawling at seven months. At 10 months, he was blowing into a kazoo—Mozart probably didn't do that until he was at least a year! At 10 and a half months, Alex was taking his first steps. At 12 months, he was playing hide-and-seek, and at 12 and a half months, he began saying his first words.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.

At 13 months, he was struck by a drunk driver.

The development books were thrown out. Alex's severe brain injury destroyed most of his former functioning, leaving only unanswered questions. As we dealt with emotions ranging from shock to despair, we somehow tapped an inner source of strength. Believing that "normal" development was still an appropriate goal, we embarked on a plan to bring our child back.

Days turned to weeks, months to years. Therapists manipulated him, doctors prodded him, lab technicians poked at him, but nobody seemed to have any solutions. Alex made some progress, but each subtle improvement was excruciatingly slow and required tremendous effort. Success came in the smallest of gains—the increased movement of his finger or the turn of his head. What once seemed the simplest of tasks—grasping a rubber ball—now appeared hopelessly complex and utterly unattainable.

And yet, transformations were occurring. Not so much in Alex, but in us. Slowly we began to appreciate the little miracles that were never mentioned in the child development books. Like the day when, for the first time since the accident, a tiny corner of Alex's mouth curled up in a barely noticeable smile. Or when we first realized that the "gleam" had returned to his eyes. Those small events would once have been overlooked. But now, with eyes opened by tragedy, we had come to recognize the magnitude of such moments.

In the midst of our transformation came another miracle—the birth of our second son, David. As David grows, our sense of wonder deepens. His developmental

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Fathers' Voices

pace is stunning. He initiates movement without our intervention, as if compelled by some innate mechanism. Nor is it necessary to "stimulate" his responsiveness; he interacts as if by magic. Miraculous, "impossible" tasks, like grasping a rubber ball, he accomplishes effortlessly.

Child development books would describe David's progress as "normal" or "average." We know better. We have been offered a glimpse at the complexities attendant with every blink of an eye and every twitch of a finger; with that vision comes a newfound appreciation for the miracle of life. Development—any development—is nothing short of exceptional.

We once viewed the maturation process as something to expect. We now see it as something to revere. We have been blessed with two precious gifts, and for us, each new day is a cause for celebration. **EP**

Louie Mauro lives with his wife, Donna, and their two sons, Alex, 5, and David, 2, near Sacramento, California. Louie is a Deputy Attorney General with the California Department of Justice, and also serves on the Board of Directors of the Head Trauma Support Project in Sacramento.

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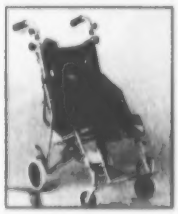

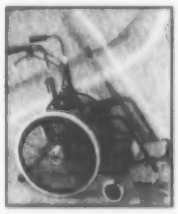

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Tony Coelho

"Epilepsy gave me a mission."

Tony Coelho authored the Americans with Disabilities Act when he was a Democratic congressman from California. Coelho, 52, is now president and CEO of Wertheim Schroder Investment Services, a New York-based asset management firm, and chairman of the President's Committee on Employment of People with Disabilities.

Coelho lives in Alexandria, Virginia with his wife, Phyliss and two teenage daughters, Nicole and Kristi.

Richard Marriott, chairman of Host Marriott Corp, talks with Coelho at the President's Committee on Employment of People with Disabilities annual conference, in Atlanta, May, 1994.

I was a happy kid, living and working on the family farm in California, good in school, fair at sports and popular with girls. I wanted to be a trial lawyer and later, a priest. I had no idea that my life would not go as planned.

Everything changed when the pickup truck I was riding in flipped over. I got a nasty bump on the head, but you recover fast when you're 15.

I was milking cows when I had my first convulsion—a grand mal seizure. My parents, children of religious Portuguese immigrants, sent me to faith healers, seeking a supernatural explanation for what they couldn't understand. But the convulsions continued.

After high school, I entered Loyola University in Los Angeles, where I was president of the student body. In my senior year, I applied to a Jesuit seminary. They were overjoyed to accept me, an intelligent young leader deeply committed to serving God.

But, the cross I was destined to carry was the stigma of disability, not the crucifix of a priest.

During a routine physical for the seminary, I learned I had epilepsy. Like many with unexplained physical or mental problems, I felt freed. Now that it was understood that my repeated seizures resulted from a brain injury and could be treated, I thought everything would return to normal.

I realized my naiveté when I broke the news to my father.

"No son of mine has epilepsy!" he shouted.

"This one does!" I shouted back.

I then discovered that my parents had known about my epilepsy years earlier, but wouldn't accept it. Centuries-old prejudice held a firm grip on their minds. In medieval times, people who had "fits" were considered possessed by the devil, and for some people, this belief persists.

Coelho at age 10.

Relief, but persecution

The diagnosis which had given me such relief was the beginning of the personal and institutional persecution so familiar to people with disabilities.

I was expelled from the seminary. Sorry, they said, but epileptics are not eligible for the priesthood.

When the doctor reported my epilepsy to state authorities, my driver's license was revoked. Soon after, my health insurance was canceled.

Because I wouldn't lie on employment applications, I couldn't get a job. All the offers I'd had since graduation disappeared. Not even the army would take me, though they were drafting others my age for Vietnam.

Nothing about me had changed since taking that physical, but suddenly, I was an "epileptic," an outcast.

Booze helped me through the idle days and lonesome nights. I was out of work, out of luck and out of hope, scared to face the future in a world where no one wanted me.

Hope from Hope

I had seriously considered suicide until a Jesuit priest provided me with an opportunity to live with the Bob Hope family. Mr. Hope befriended me. "If you find your way blocked," he told me, "find another route to get where you want to be."

He suggested I find a ministry outside the church, perhaps in Congress. So, I began my career in politics.

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Role Models

What I once considered a curse forced me to face life, shaped me and strengthened me. Above all, it gave me a mission as an advocate for people with disabilities, and God has favored my efforts by granting me so many pulpits from which to speak.

I'm an effective fund raiser for political and charitable causes because I am immune to rejection. Nothing can compare to the rejection I felt when my family refused to acknowledge my epilepsy. No humiliation could be greater than being marked as unworthy of serving God and your country.

Time has not erased the scars. They remain as razor-sharp reminders of that fear, frustration and anger which I want no one else to feel, ever again.

Advocacy

In Congress, I wrote and fought for passage of the Americans with Disabilities Act (ADA) to secure the rights of this nation's largest minority. The ADA prohibits discrimination in employment, transportation, telecommunications and public accommodations. It has also sparked a swelling empowerment movement, which is where our future lies.

I served 10 years in the House of Representatives and know how the system works. Advocacy is a personal matter.

No lobbyist can make the case for insurance reform like a mother whose child has been refused coverage because the only available treatment is "experimental."

No lobbyist can express the rage of someone who has recovered from a coma only to find out he cannot get the therapy he needs.

No lobbyist knows the need for personal assistants like the man who once said to me, "What good is the ADA if I can't get out of bed?"

Please, don't ever underestimate the power of your one voice and your one vote. Self-advocacy begins by understanding that rights are never bestowed; they are claimed.

We can't let one law make us complacent, especially now when we are beating at the doors of reform in health care, education and civil rights.

Our fight is not just about tearing down walls and widening doorways. It's a struggle for the soul of America to reaffirm its highest principles of equality and justice. The outcome will be a statement about who we are and who we want to be.

In today's global economy we don't have a worker to waste, yet, in the disability community, unemployment is at 24 percent, nearly four times the national average. Talented, capable people still receive pity and paternalism instead of individual sovereignty. This is bad for us and bad for the country.

Since the November elections, we've been told the people are angry. They want changes. They want results. And they want it now.

So do people with disabilities. We want the barriers removed. We want the chance to work. We want acceptance in our communities. We want our abilities recognized. We want our dignity. And we want it now.

Discrimination hardens you, but it also heightens your awareness of each person's responsibilities to others. We need to inspire those who have lost hope, and become a leadership force for new growth and prosperity. We need to take charge of the issues which affect our families and our nation because we've been waiting in line for a long, long time. **EP**

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"[K]ATELEDOSCOPE television is important for America's disability community. The network's programming helps Americans with disabilities move into mainstream life by changing perceptions."

SENATOR BOB DOLE

"[K]ATELEDOSCOPE not only gives people with disabilities a new means of communication, but television gives all Americans an opportunity to maximize abilities."

SENATOR TOM HARKIN

As one of 49 million Americans who happen to have a disability, like I happen to have epilepsy... I'm very excited about [K]ATELEDOSCOPE. It[']s uses the extraordinary power of television to communicate ideas and positive role models for our complex society.

TONY COELHO, Chairman
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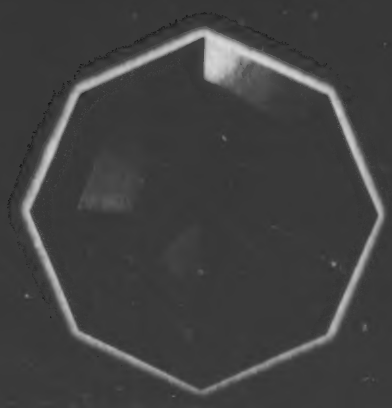

"[K]ATELEDOSCOPE is on [cable] television."

AMERICA'S DISABILITY CHANNEL

Income Tax Tips

by L. Mark Russell, Arnold E. Grant and Richard W. Fee

Families that include a member with a disability are often entitled to deductions and credits unavailable to others. Here is a summary of some items of particular interest.

Exemptions For Dependents

You can take a deduction of $2,450 for yourself, and for each person who is your dependent, whether or not the dependent has a disability. This deduction is limited for high-income taxpayers.

A person is considered your dependent if you provide more than half the person's support and the person is related to you. To determine this, compare the amount of support *you* contributed, with the entire amount of support received from all sources, including the person's own funds and government funds. Support includes money spent to provide food, shelter, clothing, education, health care, health insurance premiums (including premiums for supplementary Medicare coverage), recreation and an allowance. Support is not limited to necessities.

Medical insurance benefits, including Medicare benefits, are not considered part of support. If a dependent receives Social Security benefits and uses them toward his or her own support, the payments are considered as support provided by the dependent. State benefit payments based on need are considered support provided by the state.

If a dependent is a full-time student, scholarships received are not included in total support. This includes the value of education, room and board provided for your dependent. This also applies to payments for room, board and tuition provided for a child attending a special school even if the payments are made by the state.

Unless your child is a student, you cannot claim your child as a dependent if he or she was 19 or older at the end of the year and had a gross income during the year exceeding $2,450. If your child is a student younger than 24, this gross income test does not apply. If you claim your child as a dependent, your child cannot claim a personal exemption on his or her own return.

Medical Expense Deduction

A taxpayer is entitled to a tax deduction for medical expenses (which are not reimbursed by health insurance) for the taxpayer and his or her dependents. For these purposes, dependent is defined as above, except that the "gross income test" does not apply. For the purposes of this deduction, the person must have qualified as a dependent at the time the medical services were provided or when the bill was actually paid.

- Medical expenses are deductible only to the extent they exceed 7.5 percent of "adjusted gross income."
- Medical expenses may be deducted *only* if you itemize your deductions on Schedule A, Form 1040, commonly called the "long form."

A deductible medical expense includes any amount paid for the diagnosis, cure, mitigation, treatment or prevention of disease, or for the purpose of affecting any structure or function of the body and for transportation costs on trips primarily for and essential to medical care. This definition is interpreted broadly; expenses that you may not think are qualifying may be deductible medical expenses.

When families with children who have disabilities deduct large amounts of medical expenses, they may draw special notice from the Internal Revenue Service (IRS). To reduce the IRS's suspicions, describe your child's disability in a letter written by yourself or your child's doctor, and attach it to your tax return.

Also, be sure to store your receipts and canceled checks carefully. Good record keeping is one key to good tax planning.

Tax Credits

In addition to deductions, a variety of tax credits may be available. Unlike deductions, credits are subtracted directly from taxes due and are therefore more valuable.

- *Child and Dependent Care Credit:* If you pay someone to care for a dependent so that you and your spouse can work, attend school or look for work, you may be entitled to take the Child and Dependent Care Credit. The limit on work-related care expenses is $2,400 for one qualifying person and $4,800 for two or more persons. The credit is computed on Form 2441 if you file Form 1040 or Schedule 2 of Form 1040A.
- *Earned Income Credit:* If your adjusted gross income is less than $23,755 and you had a child with a disability (or a minor child without a disability) living with you for at least six months of the year, you may be entitled to the Earned Income Credit. You may qualify for the credit with an adjusted gross income less than $25,296 if you had two or more qualifying children living with you.

The amount of the credit is determined from tables published by the IRS. The credit varies depending on income and number of qualifying dependents.

If the credit exceeds the amount of taxes you owe, you can get a refund. Use Schedule EIC of Form 1040 or 1040A to claim the credit. The credit is also available if you use Form 1040EZ.

Figuring your taxes can be very complicated. Good luck! **EP**

Free Tax Publications

All IRS publications and forms can be ordered at no charge by calling the IRS toll-free at (800) 829-3676.

Pub. 907, Tax Highlights for Persons with Disabilities, briefly explains tax laws applying to persons with disabilities and directs readers to sources of detailed information, such as: Pub. 502, Medical and Dental Expenses; Pub. 503, Child and Dependent Care Expenses; Pub. 524, Credit for the Elderly or the Disabled; Pub. 525, Taxable and Nontaxable Income; and Pub. 915, Social Security Benefits and Equivalent Railroad Retirement Benefits.

This summary is based on PLANNING FOR THE FUTURE, *by L. Mark Russell, Arnold E. Grant, Suzanne M. Joseph and Richard W. Fee. Easy to read and understand, this 400-page book is designed as a comprehensive treatment of the life and estate planning process. The book can be ordered from* EXCEPTIONAL PARENT LIBRARY *(800/535-1910).*

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Special Camp Guide 1995.
A directory of summer programs in the northeast for children with special needs. Checks or money orders for $10.00 payable to **Resources For Children with Special Needs,** 200 Park Ave. So., Suite 816, New York, NY 10003, (212) 677-4650.

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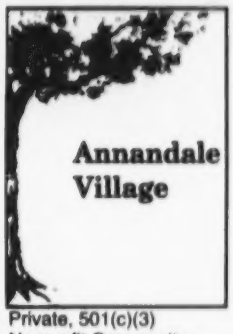

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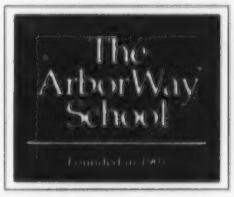

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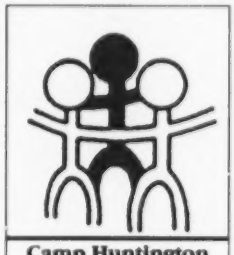

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Circle #132

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Circle # 141

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This portable, water-powered lift connects to existing plumbing to provide assistance in bathtubs and whirlpools for children with special positioning needs. The unit is operated with a hand control and has numerous accessories and covermat colors. A reclining feature is also available.

Clarke Healthcare Products, Oakdale, PA 15071-9223

Circle # 142

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Betta Medical, Sandy, UT 84070

Circle # 143

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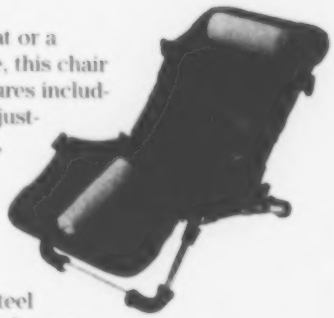

As a reclining bath seat or a portable seating frame, this chair has many special features including tilt-in-space, an adjustment for hair washing, hip flexion for children who slide forward while seated, two body straps and four body supports. The chair is made of steel tubing with non-slip pads to protect the base of the bathtub. Available in two regular sizes or an optional narrow size for smaller tubs.

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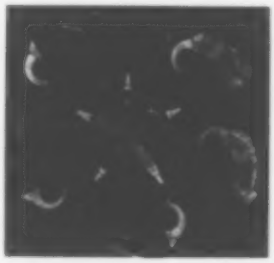

These brightly colored shells for behind-the-ear hearing aids come in pink and purple, orange and green, yellow and blue, and purple and green. Shells are translucent so one can see the working components inside. For those who do not want color, a completely transparent version is also available.

Oticon, Somerset, NJ 08875

Circle # 143

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 products for persons of all ages who have a physical, sensory or cognitive disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers in each listing are to be used on EXCEPTIONAL PARENT*'s "Free Product & Information Card." Readers can circle a number on this issue's card (page 63) to get more information on any new product featured above. Please allow three to four weeks for delivery of the information.*

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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CONNECTIONS

The Newsletter of the National Center
for Youth with Disabilities

Transition Clinic Opens:

Project Launch Welcomes Teens and Families

Two adolescents brought their families to the first transition clinic for youth with chronic illness and disability held at Shriners Hospital in Minneapolis, Minnesota, on February 6. They spent the day talking with professionals and asking many questions.

One teen had concrete goals but needed a plan: What further education do I need? Can I continue my same health insurance if I go out-of-state to school? Will my health influence my choice of careers? Can the Department of Rehabilitation Services help finance my education? How will I get a personal care attendant?

The other had more personal concerns. How do I find the assistance I need to live alone? What if I want to get married? Will the medications I take interfere with birth control?

Both wanted to know how to find a physician. "I've seen my pediatrician since I was a baby. Sometimes I think it would just be easier to stay with him."

These are some of the issues all youth with disabilities face as they move into adulthood, yet few programs exist that provide guidance for youth with disabilities in planning for all their health-related concerns, not just their medical conditions. That's why the University of Minnesota's Adolescent Health Program and the National Center for Youth with Disabilities have joined with the Minnesota Department of Health, Minnesota Children with Special Health Needs; Shriners Hospital, Twin Cities Unit; and the PACER Center to start this Transition Clinic.

... many young people with chronic illnesses are not receiving special education services....

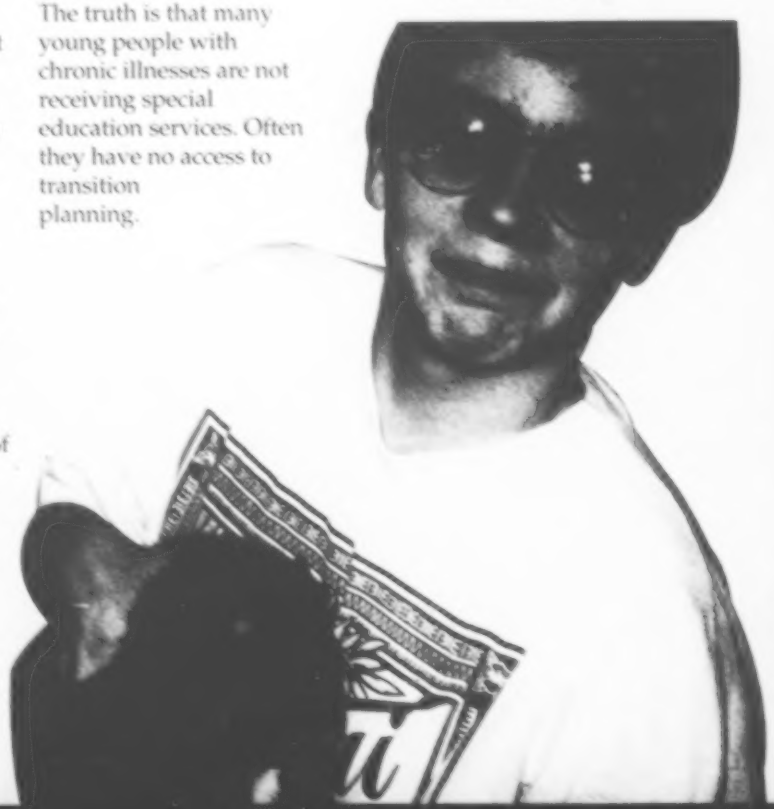
While transition planning occurs in the educational and vocational systems, health issues are not ususally considered. This clinic will be a resource to the other transition services and will work in conjunction with schools and other resources to develop comprehensive approaches.

The truth is that many young people with chronic illnesses are not receiving special education services. Often they have no access to transition planning.

Project Launch: The Independent Living Clinic for Adolescents assists young adults and their families to make successful transitions to adulthood by helping them to develop a plan that addresses issues of health, education, work, social relationships, and physical, emotional and sexual health.

Project Launch

Turn to page 70



Editor's Note:

While a teenager struggling to gain independence is the cause of many interesting (and some not-so-interesting) family dramas, often it is more poignant a challenge when the teenager has a chronic illness or disability. How often do parents expect their 21-year-old to be independent when the truth is their child has none of the necessary skills to be independent? How often does the system thwart teenagers' development of independence by keeping them in pediatric care?

If professionals want to help youth with chronic illness and disabilities achieve independence, they may just have to "re-think" their responsibilities to the adolescents with whom they work. Chronic illness and disabilities often place young people in a dependent role, precisely the opposite of their need to take control over their own lives and become adults. Teens need to learn how to make decisions and how to deal with success and failure. But they can't do it alone. To encourage independence, parents must be able to shift responsibility to the adolescent. The extent to which an adolescent can become independent depends on the degree of disability, the family's psychological support, financial situation, and the teen's motivation. For optimum development, teens with disabilities must have access to the same life opportunities as their peers, and they need to have equal opportunity to participate, succeed, and fail in those activities.

That's really what the articles on these pages are about: Encouraging independence. Building transitions. Every adolescent with a chronic illness or disability should have an "independence" plan. For most teens, planning for the future, dating, having a driver's license, being enrolled in school, and finding a job are critical to independence. Youth with disabilities may not achieve each of these milestones without special, formal attention to developing a plan. We highlight one program that is trying to fill the gap between pediatric care to adult health care. But more important, NCYD is conducting a survey to identify formal transition programs across the country. Please fill in the form on the next page if you know of one.

We also highlight some of the differences between care provided by a pediatrician and care provided by an internist that might be useful to families when considering change. We received so many positive comments when it was originally published in the fall, 1994, issue of ***Connections*** (the newsletter of the National Center for Youth with Disabilities), that we decided to offer it to a wider audience. But there are other choices and models of health care. Some families find family practice physicians meet their needs throughout the life cycle and some teens have positive and valuable experiences in school-based and other adolescent health centers.

PMR

Project Launch

From page 69

Each teen and family has the opportunity to meet with a variety of professionals. The goal, however, is to start with what the young person identifies as the most pressing needs. Most teens will not need to see every professional; the clinic allows for a variety of consultations.

- A nurse or social worker can review general health care issues, discuss insurance options, and consult on issues surrounding social activities and expectations;
- A physician trained in adolescent medicine can help a young person identify medical and physiological issues, including making plans for ongoing care and the implications for healthy sexual development. The physician can answer questions about reproduction, childbearing and sexual vulnerability; make recommendations for contraception, manage menstrual disorders, and assist in the prevention of sexually transmitted diseases;
- A psychologist can discuss psychosocial issues surrounding the transition from adolescence to adulthood—gaining independence, learning styles, managing self-care, identifying adolescent health risks and their impact;
- A vocational counselor can help a teenager evaluate past work experience, explore career interests, train and assess needs, and assist in identifying strategies to meet individual goals;
- A family resource coordinator can help the young person with disabilities and the family link up with community agencies, schools, physicians, and others as necessary.

Some young people will require additional professional assessment. For them, specialists may include nutritionists; genetic counselors; educators; psychiatrists; occupational, physical and speech therapists; and financial or legal counselors.

Project Launch is a demonstration project available at no direct cost to families or the referring professional or agency. This program will be evaluated for consumer satisfaction and perceived usefulness.

For more information, contact:

Nancy Okinow
NCYD
Box 721
University of Minnesota
420 Delaware St. S.E.
Minneapolis, MN 55455

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Calling All Transition Programs

The National Center for Youth with Disabilities (NCYD) wants to identify those transition programs across the nation that help adolescents with chronic illness and disability move from pediatric to adult-focused health care.

If you participate in, direct, or know of any formal transition program that meets one of the criteria above, complete this form and mail or fax it to:

Peter Scal
NCYD
Box 721
University of Minnesota
420 Delaware St. SE
Minneapolis, MN 55455
Fax: 612-626-2134

What makes a transition program for health care? A formal health care transition program incorporates one or more of the following elements:

Professional and environmental or institutional support for the concept of transition of health care;

Recognition and encouragement that the responsibility for decision-making and consent needs to move from the parents to the adolescent;

Professional sensitivity to the psychosocial issues of disability and chronic illness;

Primary and preventive care in addition to care for the chronic condition;

Commitment to health education.

The number of adolescents who survive into adulthood because of better medical practices is increasing all the time. Unfortunately, there is little basic information about the health transition services that are necessary to meet their needs. Descriptions and program evaluations of various models—including family practice models—are scarce.

NCYD is conducting a survey to identify transition programs; these will then be the focus of a more detailed study. A report describing the characteristics of various program models will be compiled and disseminated to a wide audience. Such information will encourage and facilitate the development of new programs.

NCYD
Box 721
University of Minnesota
420 Delaware St. S.E.
Minneapolis, MN 55455

Type or name of transition program: _____

For more information, contact: _____

Address: _____

Telephone number: _____

Fax number: _____

E-mail address: _____

Inquiries about NCYD may be directed to:
National Center for Youth with Disabilities
University of Minnesota
Box 721
420 Delaware St. S.E.
Minneapolis, MN 55455
1-800-333-6293/
612-626-2825

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Adolescents with Chronic Illness and Disabilities:

Managing Health Care Between Cultures

Moving teens from pediatric to adult health care can often be complicated. There can be many choices. Some teens receive care from family practice physicians. Some use school-based health clinics that provide appropriate referrals.

For most, the dilemma arises in moving from their pediatrician to an internist for primary care. And they can provide very different types of care.

"Training in either discipline socializes young pediatricians and internists to the unique comportment of their chosen fields," David Rosen, M.D., M.P.H., explains. Rosen has one foot in adult medicine and another in pediatrics. While aware of the limitations of stereotypes, Dr. Rosen describes the various differences between the disciplines:

Internist

- The internist is a clinical problem solver determined to come to terms with the presenting problem.
- The internist sees patients when growth and development are complete. They are less likely to expect continued improvement and development; rather, they look to remediation to ward off inevitable deterioration in health.
- The internist sees patients who are ill, often with conditions that deteriorate over time, and frequently with illnesses associated with adult lifestyle choices that include tobacco, alcohol and other drug use, poor diet, lack of exercise, etc.
- The internist sees patients who are expected to function autonomously.
- The internist communicates directly with the patient.

Pediatrician

- The pedatrician, while also a problem solver, balances the practical needs of patient and diagnostic curiosity.
- The pediatrician facilitates a child's growth and development over time and observes their patients becoming more capable.
- The pediatrician sees patients who are healthy most of the time and few are ever perceived as having direct "responsibilty" for their condition or ill-health.
- The pediatrician views families as critical to the well-being of children and adolescents.
- The pediatrician communicates with parents and other family members, often before communicating with the patient.

The National Center for Youth with Disabilities is a program of the Society for Adolescent Medicine and the Adolescent Health Programs at the University of Minnesota. Publication of *Youth Connections* is supported, in part, by project MCJ-275045 from the Maternal & Child Health program (Title V, Social Security Act), Health Resources & Services Administration, Department of Health & Human Services.

The Center's mission is to improve the health and social functioning of youth with disabilities through providing technical assisstance and consultation, dissseminating information, and increasing the coordination of services between the health care system and others. Center activities are directed at enabling youth to become full participants in their communities.

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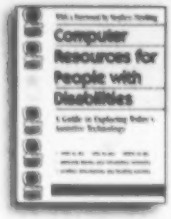

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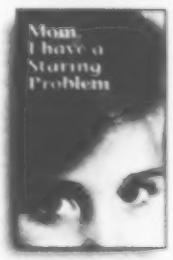

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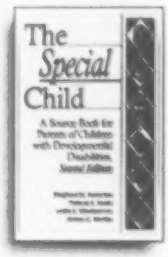

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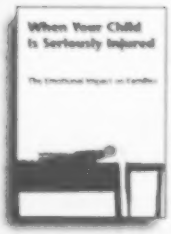

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by Emily Brush

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In school, some of the other kids ask me why I can't walk. I tell them I have something called a handicap. Maybe I'll be able to walk when I get a little older, but for now, I get around just fine in my chair. **EP**

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—Diane Brush

Emily, 8, is in the second grade at the Edith M. Griebling Elementary School in Howell Township, New Jersey. She lives with her mom and dad, Diane and Gary, and Smokey, her cat. Emily has athetoid cerebral palsy.

Emily, 8, enjoyed Thanksgiving dinner last year with her good friends, Michelle (left) and Angela (right) Tuchol.

When Emily was six and a half, she spent Easter Sunday in New York City with her family.

Emily, 7, at her Brownie Inception. With her is her dad, Gary.

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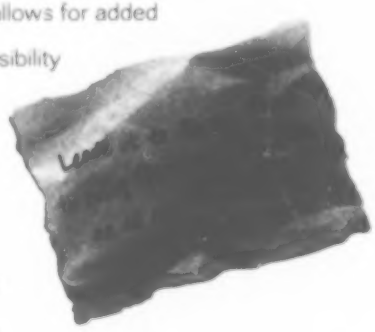

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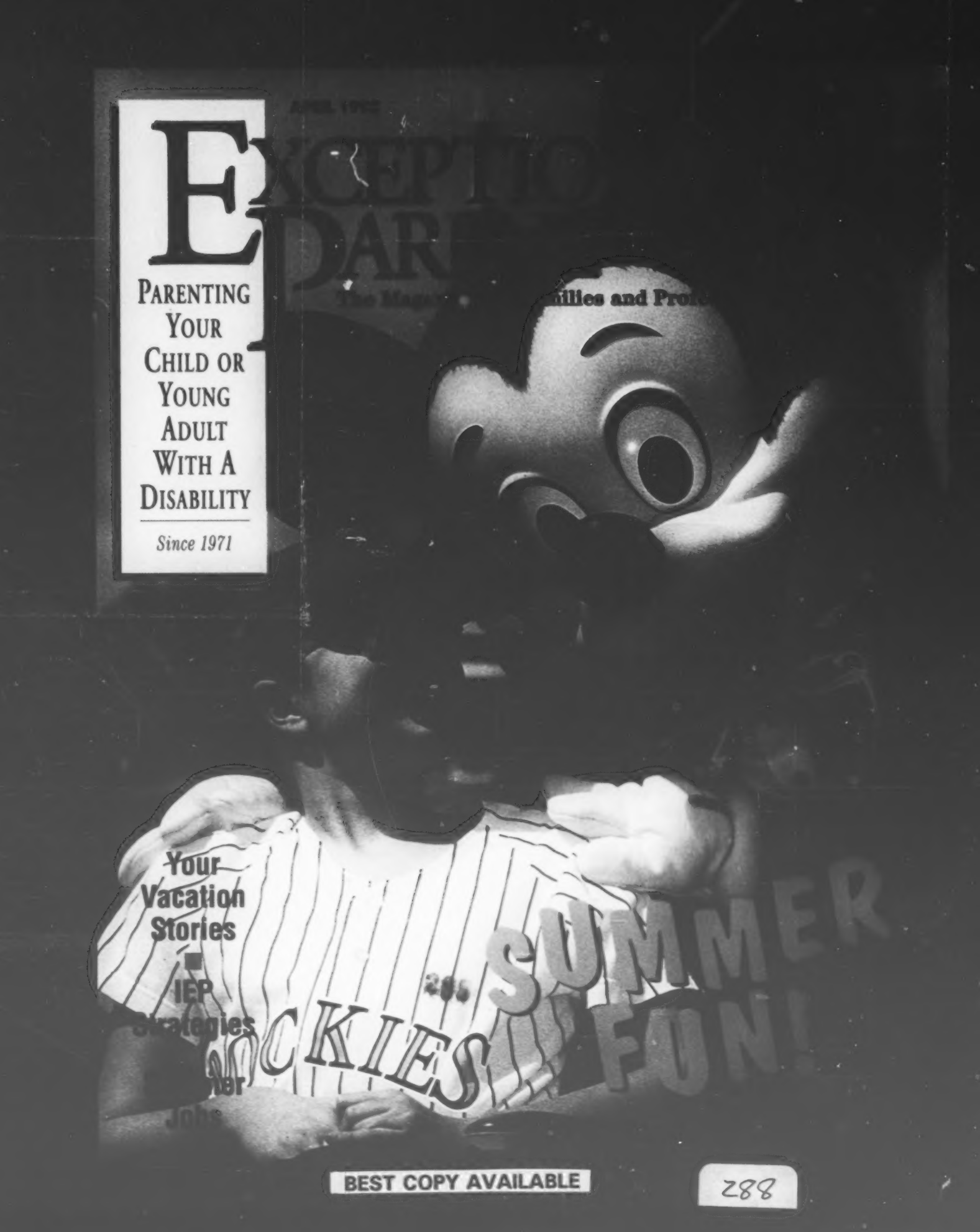

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PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

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APRIL 1995 VOL. 25, ISSUE 4

PAGE 34

Cover: *Ryan In't Veld of Belle Fourche, South Dakota with Mickey Mouse during his vacation to Walt Disney World. Ryan, who has Duchenne muscular dystrophy, spent six days visiting many attractions in the Orlando area. The trip was sponsored by Give Kids the World, a nonprofit organization that gives children with life-threatening conditions and their families all-expense-paid vacations to central Florida and its famous attractions.*

Ryan, 11, shared his visit to Disney with brother Andrew, 13, sister Elise, 8, and parents Arlen and Sue. Ryan is a fifth-grader at the Belle Fourche Middle School.

For more information on Give Kids the World, contact them at 210 S. Bass Rd., Kissimmee, FL 34746, (407) 396-1114 (voice), (407) 396-1207 (fax). Photo: Wallace Sears, Walt Disney World.

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EDITOR'S DESK

As we developed material on summer planning, we also decided to include information about jobs. Summer is the time when many young people first think about getting a job—and this important summer activity also requires planning. Unfortunately, many young people with disabilities miss out on the typical adolescent experience of summer and part-time jobs. While parents, professionals and people with disabilities have worked very hard to create educational and recreational opportunities in their communities, we don't know of many opportunities for young people with disabilities to learn the essential job skills so many of us learned on our first jobs—getting to work on time, meeting deadlines, getting along with co-workers and doing what we are told—even if we don't like it. These experiences often help us to discover new interests and abilities. In fact, the summer job I held after my first year at college in 1954—working at a camp for children with disabilities—changed my career plans.

STANLEY D. KLEIN, PH.D.

We hope readers will encourage employers to begin offering job opportunities to young people with disabilities. One of our summer editorial interns in 1994 was a high school student with special health care needs.

All kinds of fun

Thanks to the many readers who responded to our request to share stories about memorable family vacations. It has been exciting to read these wonderful stories of how parents and children are finding ways to enjoy a variety of different types of vacations. Though not every vacation described will be the right fit for every family, we know these stories will inspire readers.

We are especially grateful for the kind assistance of the wonderful people at Walt Disney World for helping us to create a great cover. Thanks to photographer Wallace Sears for his great photo of Ryan In't Veld and Mickey Mouse.

Changes in Washington

Networking describes key changes in Congress that have taken place since the November elections. We congratulate the new congressional committee chairpersons and staff members. We look forward to helping them get their messages to our readers.

Some of the concerns that advocates have raised have been addressed. At the same time, we encourage readers to share the suggestions of Richard Epstein, our *Health Insurance Troubleshooter* columnist, with their elected representatives. Parents, people with disabilities, advocates and political leaders can be proud of the wonderful improvements in attitudes about people with disabilities as well as the ever-increasing opportunities and expectations for participation in community life that have come about because of important legislation. However, there are many areas that still require change or need to be improved. Our leaders welcome and need our input.

Education Program Awards

It's time again to invite nominations for this year's *Exceptional Parent Annual Educational Program Awards.* Programs will be judged on criteria such as attention to the needs of the whole child—academic, social and recreational; teacher support and parental and community participation.

The awards—known in the past as the *Mainstreaming Awards* and *Inclusion Awards*—recognize good educational choices for parents and children. Although we are advocates of inclusion when it includes the necessary support services, we realize that there are successful programs that are not inclusive.

Entries, of 500 words or less, should explain the success of the program. Also, please send photographs. Send nominations to *Exceptional Parent Annual Educational Program Awards,* 209 Harvard St., Ste. 303, Brookline, MA 02146. Deadline for entries is July 1, 1995.

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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 66. BPA International Consumer Magazine Membership Applied for August 1995.

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LETTERS

Struggling for Inclusion

After reading the letter "Inclusion Article Misleading" (November 1994), I felt a reply was needed. It is obvious that J.R. in New Jersey and her husband are having a difficult time effectively "including" their son. It is always a struggle—no matter the family, the child, the disability or the community.

In responding to the article "Making Inclusion Work" (September 1994), J.R. characterizes the services Angela Hart receives as "amenities." They are not. They are Angela's civil rights as dictated by the U.S. Constitution, the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA).

In her letter, J.R. describes her struggle to "convince" her daughter's team to meet more often. The article about Angela's inclusion describes a program, not the path to that program. This program is not exceptional; there are programs like it all over the country—some better, some not as far along. However, rarely do programs like this happen through "convincing." I know.

When we lived in Connecticut, we struggled long and mightily. We often got the services our child was entitled to only after our lawyer attended meetings that we legally called on our own. Many, if not most school districts, will provide services only when they have "a gun to their heads"—very sad, but very true. (We have since moved to a more welcoming school district in Kansas.)

J.R.—Your child will only participate and flourish in an inclusion program if you want this for him and are relentless. If the struggle is too challenging in your own community, you may find it feasible to explore other communities. If not, circle the wagons and get support from local groups and other parents, including the parents of your child's peers who do not have disabilities. Be prepared to make friends and enemies and enrich your lives and the lives of those with whom you come in contact.

continued on page 6

From Grief to New Dreams

I was very impressed by "Grieving a Dream" by Susan Blanchard (October 1994). It brought me back to my own grieving process more than 35 years ago…

I married late in life and my first child was born with Down Syndrome. Receiving "the news" from my doctor when Lisa was three months old was a traumatic experience. I still recall my husband's response to my distress. He asked me to answer this question honestly: "Is Lisa any less precious today than she was before the doctor gave you the news?"

Because I have always been extremely honest about my feelings, and maybe because I had always dreamed of a daughter who would go to college, my answer was "yes." All my dreams for Lisa had been shattered.

Lisa and Betty Pendler celebrate Betty's birthday in 1988.

My grieving manifested itself in horrendous emotions—I wished I were dead; I wished something would happen to both Lisa and me. I was very jealous of my three girlfriends, who also had married late in life, but had given birth to "normal" babies. I still recall how incredulous my husband was when I confessed that when I gave Lisa a bath, I was tempted to fill the bassinet up to the top.

These thoughts and feelings aroused incredible guilt, and I was sure I would be punished for them. I thought there was something radically wrong with me until I read Wolf Wolfsenberger's research on the initial reactions of parents to the news that their child has a disability. Wolfsenberger mentioned emotions like alarm, ambivalence, anguish, avoidance, bitterness, confusion,

Lisa (right) and brother Paul show off their Easter parade outfits in 1961.

denial, depression, despair, disbelief, envy, guilt, impulse to destroy, overidentification, remorse and shame—I could identify with them all.

As Susan Blanchard stated, the grieving process is a continuous one. Even the best adjusted parent will face many occasions that re-evoke intense feelings of grief. Feelings never completely disappear; they remain part of our emotional life forever. It is important that we acknowledge that these feelings are a normal response to an abnormal situation.

I believe it was healthy for me to admit to these feelings and to talk about them. Shedding my guilt about these feelings freed me to help Lisa become the terrific human being she is. I became able to have dreams and visions of the things Lisa would be able to do. I worked hard at making her as independent as possible, and I "let go" at a very early age.

Thirty-five years ago, most parents of children with disabilities had nightmares about the future, not the dreams and visions of today's young parents. I urge all of you young parents to move beyond grieving, and start dreaming of the many things your children can do. With more integration, higher expectations and more risk-taking, our sons and daughters will reach new heights.

Betty Pendler
New York, New York

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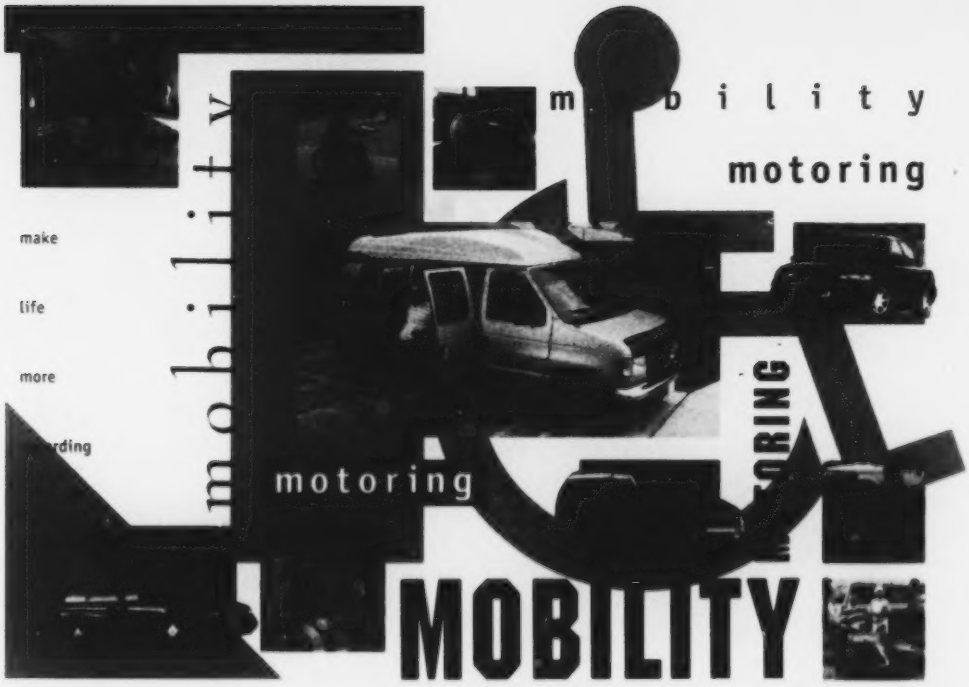

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Circle #3

LETTERS

continued from page 4

Inclusion of J.R.'s child will benefit every child, teacher, parent, civic leader and administrator who rubs up against it. It is up to J.R. and her husband to carry on the struggle. J.R., we are all here to help; your struggle is ours. Include us in it and include those close to you, too. You cannot do it alone.

H.R., Kansas

Responding to Albert Shanker

As a parent-advocate and the parent of an "included" child attending school in New York state, I was surprised to see Albert Shanker's article ("Inclusion and Ideology," September 1994) reproduced in your magazine.

While I understand that not all parents want or are ready for inclusion, I also believe that special education should not be "segregated." Separate schools and classes create concentrations of similar disabilities. In such situations, where are our children's role models? How does a child with a speech impairment learn to speak if no other child in the class can speak?

For many years, speech therapists told me that my child "did not communicate with her peers" when placed in a therapy room with two other children with disabilities. However, when mainstreamed at lunch, she had no difficulty communicating successfully. The problem was that she had nothing to say to the two children in the therapy room.

My daughter's inclusion has been a success because it has been done properly. I thank my school district and all the staff and parents who have worked very hard to make it so. We were pioneers who led the way for others.

The inclusion movement does not

continued on page 8

Tell us about...

...experiences with genetic counseling.

***Write to:** Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

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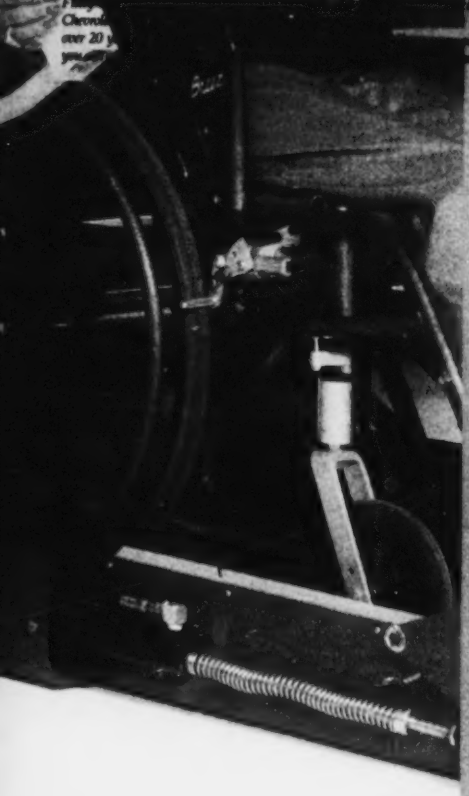

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continued from page 6

seek to remove the choice from parents but to ensure that all parents are truly given the opportunity to examine a full array of options. I agree with Mr. Shanker that sweeping policies that determine what is "good for all" should be viewed with skepticism. But who will play God and determine which child is to be given a chance?

C.F., New York

Best of Both Worlds

I wanted to take this opportunity to let others know what a wonderful magazine *Exceptional Parent* is. I have received only a few issues, but I truly enjoyed them. They have been informative, encouraging and supportive.

Exceptional Parent is the perfect title because having a child with a disability makes our lives truly exceptional. We have a three-year-old daughter with Tay-Sachs disease, a progressive, neurological deterioration which leads to death in early childhood. Naturally, we were devastated when we found out, but our daughter seems happy, feels loved and gives so much love back to us.

We also have eight-month-old twin daughters who do not have Tay-Sachs. We feel really blessed to have the best of both worlds. Our lives feel so full and rich with all of our experiences. We have really learned to appreciate all of our family and friends.

D.R. & L.R., Ohio

Thanks from a Grandparent

I'm writing to you about my grandson, Andy, who has Down syndrome. Before Andy was born in 1991, I had never even heard of Down syndrome. We knew there was something wrong with Andy, but we didn't know what. It took the doctors four days to find out.

Andy started attending a school for children with disabilities by the time he was 18 months old. This is where I found out about *Exceptional Parent*. One of Andy's teachers gave me a copy, and now I subscribe. I read it and learn something new all the time.

I would like to thank you for the great job you are doing for kids with disabilities. The information you provide is invaluable to people like me.

W.G., Tennessee

Problems with Search and Respond

I am really pleased that you will begin printing names in the *Letters* section for those who wish to have this information printed. However, I am disappointed that you will not be printing names and addresses in *Search*.

Although I understand your reasons, my disappointment has to do with my experiences responding to *Search* letters. I have responded to a handful of *Search* letters over the past two to three years, but have never once received a reply, nor have I seen my responses printed. Okay, maybe my responses were not the best choices to be printed in the magazine, but I don't want to believe that the parents who received my response letters chose not reply to me personally. That leaves me with this question: "Were my letters actually received and forwarded by *Exceptional Parent* magazine?"

It's frustrating to make efforts to connect with others, but not even know if my letters made it through. It has soured me somewhat to the idea of responding to any more letters. I haven't yet tried to do a *Search* myself, but perhaps it is time to try. You can bet I will reply to every response I receive.

Would you at least consider mailing a postcard to responding parties to acknowledge receipt or to indicate that our letters have been forwarded?

Rosanne B. Thorn
Lynn, Massachusetts

EDITOR'S NOTE: Thank you for your suggestion. We have started acknowledging all SEARCH and RESPOND letters received in our editorial offices. All responses to SEARCH letters are forwarded; due to space limitations, only a small fraction can be published in RESPOND. Space limitations also prevent us from printing all the SEARCH letters we receive.

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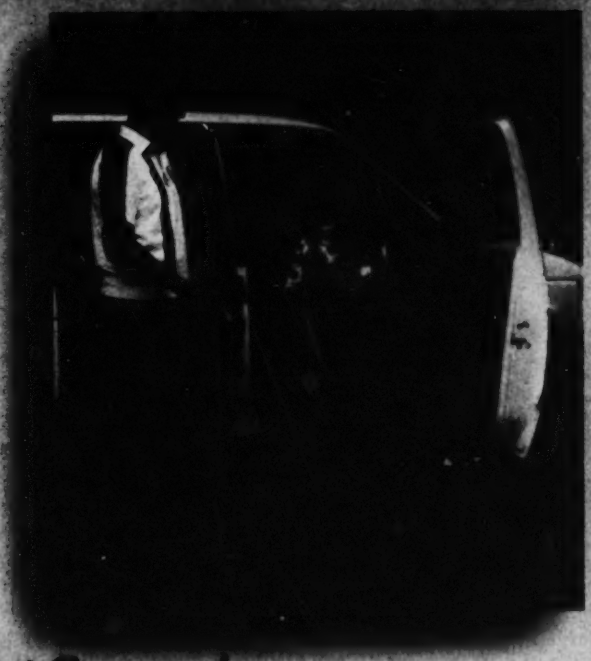

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SEARCH

One Twin with Down Syndrome

I have fraternal twins—a boy and a girl—Cameron and Catie. The twins have a close bond with each other. Cameron has Down syndrome, and is very high-functioning. We try to treat him like our other children, with maybe a little closer attention to helping him develop language and appropriate manners.

My main concern has to do with educational planning. I want to do what's best for each of them and both of them. Catie presently goes to an early childhood program with Cameron, and it has worked out great. But how long can I keep them together without holding her back? Catie wants to go to HeadStart with Cameron, but she's ready for kindergarten.

I would like to hear the first-hand experiences of other parents with a similar situation.

N.M., Minnesota

Swinging Objects

My son is 10 years old and has Down syndrome. He takes Synthroid for hypothyroidism, but has no other physical impairments. However, since he was a baby, he has had a tendency to focus on objects that he can hold and swing around. This behavior is almost always accompanied by talking to himself and, sometimes, by spinning in circles.

As he's gotten older, this need to swing objects and talk to himself has become stronger. It has become a problem at school. He seems to "zone out" at these times and becomes angry when we interrupt him. We've come to our wit's end in trying to understand and lessen the frequency of this behavior, if not eliminate it altogether. Any suggestions would be greatly appreciated.

C.T., New York

Sanitary Pads

My 10-year-old daughter is lovely, funny and, quite simply, beautiful! She has cerebral palsy—athetoid type—and is a quadriplegic. She has total bowel and bladder control. She can knee-walk and crawl and has lots of movement, both controlled and involuntary.

My daughter will soon be dealing with puberty and the beginning of her menses. I am searching for a sanitary pad that will actually work and stay in place. Her body build is slim and petite. Physical appearance and fashion are very important to my daughter, so it is very important that we find a pad that won't be visible and won't leak. I'll be very grateful for any suggestions.

M.K., Arizona

Stressful Car Rides

My 26-month-old son, Austin, does not have a specific diagnosis, but has been labeled "centrally hypotonic." Austin becomes very upset when riding in a car in a car seat. Because he is still basically non-verbal, he is unable to explain what is bothering him.

Austin has had—and still has—some sensory processing problems including a lack of response to pain. He is often unaware of food in his mouth and will hold it there for prolonged periods. Austin loves rough-housing with his siblings and enjoys movement-oriented activities. He walked at 23 months.

continued on page 12

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SEARCH

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We have tried different car seats and different seats within the car. His occupational therapist has checked his positioning in the seat and feels he is physically comfortable. However, he becomes upset immediately when we put him in the car—crying, screaming and holding his breath until he passes out, sometimes four or more times during a 15-minute car ride.

While riding in the car, we try to calm him—first with distractions, and then with a bottle or pacifier. We are looking for any ideas or activities to help make car rides less upsetting for Austin and less stressful for us and for his siblings.

C.R., Ohio

EDITOR'S NOTE: Editorial Advisory Board member and Ask the Doctor columnist David Hirsch, M.D. responds: "It sounds like Austin has global delays. I would also be concerned about his vision—especially the way he perceives moving objects—as well as his hearing and balance. I would also want to know if he has any problems with sweating or regulation of body temperature. Because of Austin's lack of response to pain, I would suggest he be evaluated for the possibility of a peripheral sensory neuropathy."

Desperately Seeking Van

My 17-year-old daughter has cerebral palsy and uses a wheelchair. She will never walk and I am finding it increasingly difficult to lift her in and out of our car.

We desperately need a wheelchair van—one that will not break down in the middle of nowhere since we live in a rural area. Many agencies have offered to help us adapt a van to accommodate Wendy, but we must find a van first. We cannot afford a good used van, and we do not have enough money to make monthly payments on a new one. Does anyone know of an agency that would help us obtain a van that can be adapted or one that is already adapted?

A.M., Arkansas

EDITOR'S NOTE: Editorial Advisory Board member and Ask the Doctor columnist David Hirsch, M.D. suggests that C.T.'s son be evaluated by a developmental behavioral specialist for the possibility that he has a pervasive developmental disorder (autistic-like characteristics) in addition to Down syndrome. Dr. Hirsch also recommends that the child's vision and hearing be carefully evaluated.

Maternal Disomy of Chromosome 14

My youngest daughter, Elyse, 4, has been diagnosed with a maternal uniparental disomy of chromosome 14. This means she received two strands of chromosome 14 from me, rather than receiving one from me and one from her father.

Doctors tell us she is one of a few children in the world with this disorder. We are looking for information about this condition and contact with other families.

J.T., New South Wales, Australia

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Circle # 73

continued from page 12

Omphalocele

My six-month-old daughter was born with a large omphalocele; her entire liver was outside of her body. I am looking for information about the development of children born with this condition. I'd like to know about things like growth patterns, motor skills, weight gains/losses and feeding difficulties.

L.S., Connecticut

Dandy-Walker Syndrome

Our five-year-old son, Michael, was diagnosed with a variant of Dandy-Walker syndrome at six months of age. My husband and I carry recessive genes for this disorder. Michael's symptoms include low muscle tone, an extra finger, a large head, a malformed cerebellum and a lack of balance and coordination. At the age of four and a half, he is the size of a two-year-old.

Michael is non-verbal but is very receptive and expressive. He uses some sign language and picture books to communicate. He does not stand without support, but he can crawl and walk with a walker.

We would like to hear from parents and professionals who have experience with Dandy-Walker syndrome. We would also like to hear from families who carry a recessive gene for this disorder. We want to have another child, but know there is a risk involved.

C.K., Colorado

EDITOR'S NOTE: The Dandy Walker Syndrome Network (5030 142nd Path West, Apple Valley, MN 55124; 612/423-4008, voice) can provide information about the syndrome. They can also help you make contact with other families in the U.S., Canada and England.

Autism and Spina Bifida

I am the mother of a four-year-old son who was born with spina bifida and also has autism. We have not heard of another child with the same challenges. We would like to hear from anyone who has a child like ours.

M.K., Iowa

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT'S 1995 Resource Guide* (January 1995).

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RESPOND

Deafness and Motor Impairments

T.K. (December 1994) is the parent of five-year-old Eleanore, who was born with hypotonia and cerebral palsy affecting the right side of her body. Eleanore has always been exceptionally visually alert and socially aware. Though making steady progress in motor skills, she did not develop language. Last summer, she was diagnosed as profoundly deaf. T.K. asked for positive stories about children with motor impairments and deafness, especially those whose deafness was diagnosed late.

My 14-year-old daughter, Justine, has athetoid cerebral palsy and is also profoundly deaf. I learned Justine was deaf when she was four months old, however, it took me at least five years to become fluent in sign language.

Justine is mainstreamed in a public high school. She uses American Sign Language and attends school with an educational interpreter/aide. She plans to attend college or technical school. Justine recently got a laptop computer that also functions as an augmentative communication device so she can communicate more easily with people who do not understand sign language. Justine's expressive signs are hard to understand because her arms and trunk are most affected by her cerebral palsy. This makes the augmentative communication system essential for her.

My daughter is beautiful, bright and very outgoing. She has a new boyfriend, who is hearing and uses a wheelchair; they communicate with the aid of the computer. Justine's future looks bright, although 14 years ago, I did not think so.

As for your daughter, Eleanore—she needs language, and fast! A late diagnosis of deafness is not uncommon, but that makes the challenge for you more difficult. My advice is to learn as much sign language as you can, so you can give Eleanore a language base.

The best way to learn sign language is to be with people who are deaf. If Montana has a state school for the deaf, they probably offer sign language classes. Another idea is to bring deaf people to you. We have personal care workers in our home; in the past, we have hired deaf women.

You will need to access the deaf community to learn their language, however, Eleanore may never be accepted as a full-fledged member of that community. Many deaf people identify themselves as members of a cultural and linguistic minority group. Most do not think of deafness as a disability.

Justine attended the Wisconsin School for the Deaf for many years, but she is accepted better now as a mainstreamed student in a "hearing school."

Since Eleanore has coordination problems and limited use of her right arm, you might have her evaluated for augmentative communication. At the same time, you should encourage Eleanore to sign for herself. Many signs require fine motor coordination, however, you and your family will be able to understand her signs. Justine's signs aren't perfect, but I can understand them, and others who know her well can, too.

I can tell by your letter that you have positive goals for Eleanore, and so you should. Nothing in my life has been as rewarding as raising Justine. I couldn't be prouder of her accomplishments. She will take the world by storm, and so will Eleanore!

J.E., Wisconsin

Down Syndrome and ADHD?

J.G. and J.J. (February 1995) are the parents of four-and-a-half-year-old James, who has Down syndrome. Professionals consider James to be very high-functioning, but some feel he may have attention deficit hyperactivity disorder (ADHD). One psychologist has suggested that the use of Ritalin may be appropriate. J.G. and J.J., who describe their son as a "typical class clown," worry that they will be "trading James' playful personality for a better-behaved child."

Our son, Matthew, is almost five and sounds like a double for your James. We always said Matthew was "hyper," but by the time he was three, we were having a great deal of difficulty coping with his behavior. We tried working with the parent educator at Matthew's early intervention program to develop strategies that would help him. But by the time he turned four, Matthew was totally out of control.

Last spring, we sought help from professionals who had special expertise in behavior modification for children with disabilities. While professionals would not officially classify Matthew's problems as ADHD, we agreed to put Matthew on Ritalin temporarily while we worked closely with the behavior therapist. We started him on the lowest possible dosage (5 mg., twice a day) and never needed to increase it.

Matthew's behavior problems seemed to stem from the fact that he is so high-functioning and has such a great sense of humor. When he "got going," he found it difficult to "turn it off" and relax. We tried Ritalin because he could not control himself enough for behavior modification to work. While it's true he was quieter and a little less "spunky" while on Ritalin, the drug made it possible for us to implement the behavior training.

In September, Matthew started a full-day program at a parochial school for children with special needs. I would give him his first dose of Ritalin in the morning; his teacher gave him the second dose at lunch. One day she forgot to give him the second dose and called me to say that he seemed much more "alert, playful and verbal" than she had ever seen him. We decided to try giving him only the morning dose. He did so well in the afternoons without it, that we eventually discontinued the morning dose as well.

Matthew has been off Ritalin for almost four months now. He is doing wonderfully in school—his teacher has never had a problem with him and probably thinks we are crazy for ever putting him on it in the first place. He constantly comes home with awards and certificates

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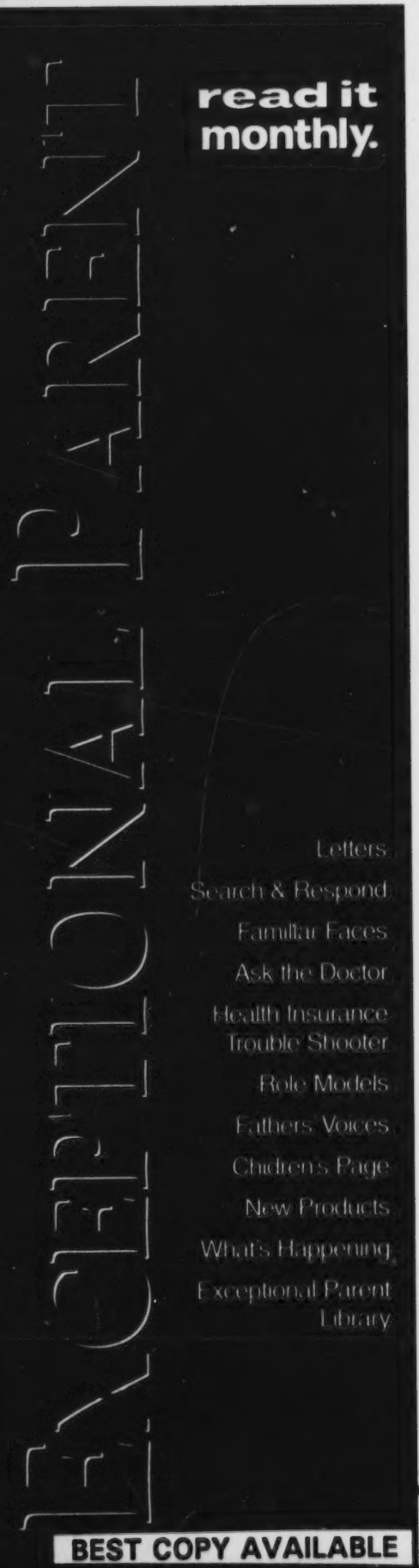

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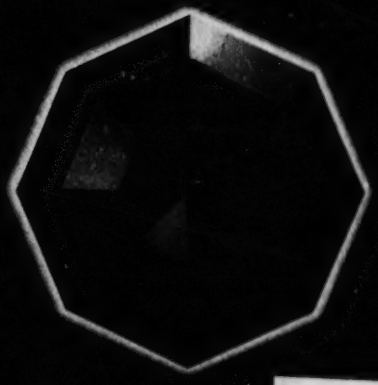

AMERICA'S DISABILITY CHANNEL

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Don't let us mislead you, Matthew is still quite a "bugger" at home, to say the least, but even without the Ritalin, he still responds to behavior modification techniques without the battles we originally encountered.

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L.N. & J.N., Pennsylvania

Encephalocele/Microcephaly

J.H. & T.H. (February 1995) have a two-year-old daughter, Emily, who was born with microcephaly (small head) and an encephalocele (opening in the skull) which was closed surgically at seven months. Emily subsequently developed hydrocephalus, a seizure disorder and bilateral optic nerve hypoplasia. J.H. and T.H. were looking for parents of a similar child or anyone else with information on this type of encephalocele.

My seven-year-old daughter, Monica, was born with an occipital encephalocele, microcephaly and amniotic band syndrome (caused by constraint in the uterus and resulting in deformities of her right arm and hand). Her encephalocele was repaired when she was 48 hours old. Happily, she did not develop hydrocephalus, but she has severe mental retardation, cerebral palsy and bilateral optic nerve hypoplasia. She is legally blind and has a seizure disorder.

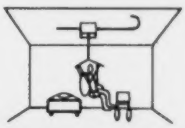
Monica took her first steps just before her sixth birthday. She now walks independently around our home, however, her balance is not very good. There's no keeping her down, so for her own safety, she needs to wear a crash helmet.

Monica attends an integrated morning kindergarten and an afternoon special education class at our local elementary school. Acceptance by her peers and school staff has been exceptional.

Monica is non-verbal and uses augmentative communication to answer yes/no questions with some success. She also reaches out for objects she wants; for example, she will choose between a cup and bowl to indicate whether she wants to eat or drink. Her school is working on expanding the number of messages she can communicate on her augmentative communication device.

I consider myself very lucky to have Monica in my life. The affection she gives is so pure and without ulterior motives; we should all be that way!

L.P., Connecticut



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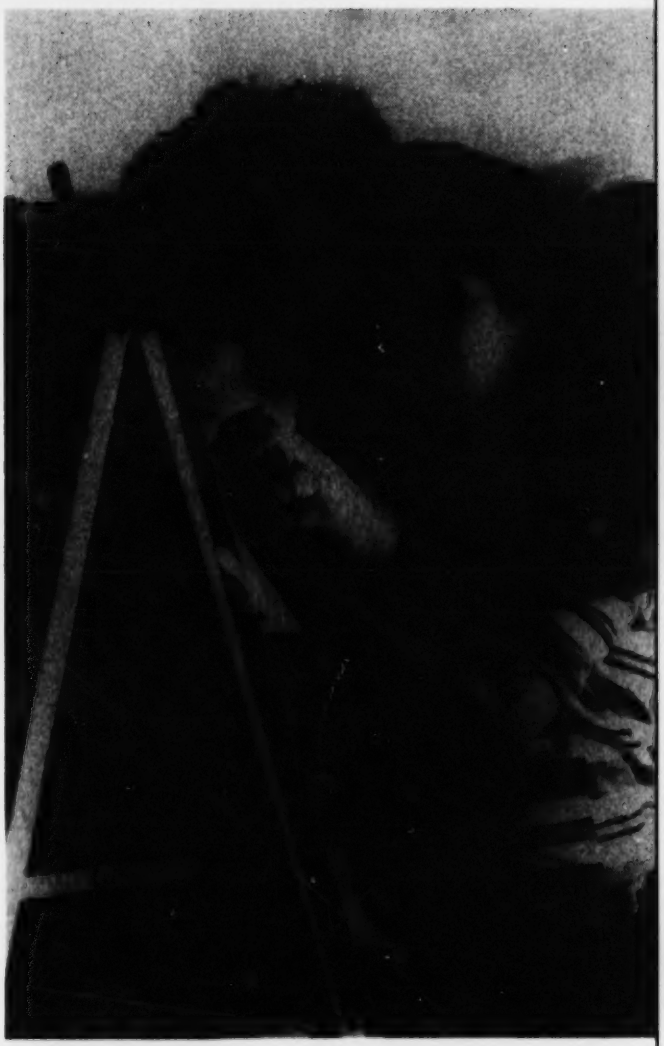

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Tom Sullivan, 48, is the author of seven books. His autobiography, IF YOU COULD SEE WHAT I HEAR was made into a film in 1982. Sullivan has also appeared on television in "Highway to Heaven," "Fame," "Mork & Mindy" and "WKRP in Cincinnati." He was a special correspondent for ABC's "Good Morning, America" from 1979 to 1982, and has written and produced several films for television. Sullivan's most recent book is SPECIAL PARENT, SPECIAL CHILD (G.P. Putnam's Sons, 1995; available through Exceptional Parent Library, 800/535-1910), a collection of interviews with six parents of children with disabilities. Sullivan and his wife, Patty, live with their two children in Denver, Colorado.

I was born three months premature in 1947 in a hospital just outside Boston. Too much oxygen in my incubator caused a filament to form over the corneas of my eyes, a condition known as retrolental fibroplasia. As a result, I'm blind. However, blindness may have been the best thing that's ever happened to me. I've enjoyed a world of senses that many people never take the time to appreciate. This appreciation didn't come naturally; it was molded by the love and dedication of my parents.

I cannot imagine what it was like for my parents to sit in the office of the most famous ophthalmologist of the time and listen while he told them they had a blind son. My mother still quotes him today: "Mister and Missus Sullivan, take him home and

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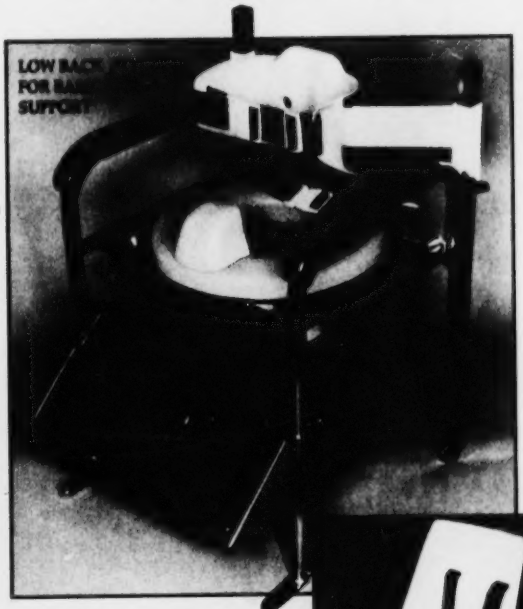

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love him. Or institutionalize him. Those are your only alternatives." My parents chose the first option; they took me home and loved me.

Recently, my mother has begun to talk about my childhood. It saddens me to hear how painful it was for her to raise a blind child. However, she believed her child should not be limited by his disability.

Sullivan attends his daughter Blythe's 21st birthday party, in 1991, with his mother, Marie.

When I was five years old, I was sent to the Perkins School, a boarding school for blind students less than an hour away from my home in Boston. Every Friday night, my parents brought me home for the weekend.

My mother still talks about the first time they brought me to Perkins: "I watched this little child being taken away by a very kind house person. You got the message that you were not going to be with us and I had to stand there while you kicked and screamed and fought them." Even at five, I understood that if I weren't blind, I wouldn't have had to be at that school. I knew that I wanted to be included with sighted children.

Extracurricular activities were my ticket out of loneliness, and I was blessed with parents who allowed me to become all the things I hoped to be. Whenever my parents were told I couldn't do something, they found a way

Sullivan with (from left) son Tom, wife Patty and daughter Blythe.

to allow me to do it. For instance, once they knew I was musical, they did everything possible to bring music into the house. My father would bring barroom musicians home at night and we'd play Irish songs until four in the morning. Then, he found out that I liked gospel music. Picture a white Irish Catholic father taking his son to a Black church so he could sing gospel music. He didn't care what it took. He just wanted me to be happy.

Painful times

My parents did everything possible to make sure I spent my time with children who could see when I was home from school. But no matter how hard they tried, there were moments that were incredibly painful. I would stand in my backyard, listening to the sound of other kids playing baseball down the street. Every time a boy hit his baseball with his bat, I picked up a rock and hit it with a stick.

One day when I was doing this, a kid passed by and shouted, "How you doin', blindey?" At that moment, I knew that he thought of me as different. It hurt.

After that, my father began designing games that I could play with the neighborhood kids—a buzzer on a basket so I could shoot hoops in the driveway; baseball played with a volleyball bounced on the cement, me swinging at the sound.

I also remember the time my father bought me a pony. That summer, I charged a nickel for any neighborhood kid who wanted a pony ride.

Parents of courage and vision

The hardest concept for a person with a disability to understand is the balance of interdependence: How much can I do alone, and how much help must I ask for? This leads to one of the hardest questions for parents: When do I let go?

My mother remembers my first day at Providence College. After checking in, my parents watched while I tried to find the cafeteria. My mother immediately thought back to the day they had brought me to Perkins: "I cried just like I did when you were five. I didn't want to help too much or be in the way. I had to watch you struggle in a completely strange place for this independence."

To be fair, I wanted my freedom, but I would have been just as happy to go back home. Freedom is frightening. You want it, you work for it, you scramble to achieve it, but it's frightening. A blind person is limited by the

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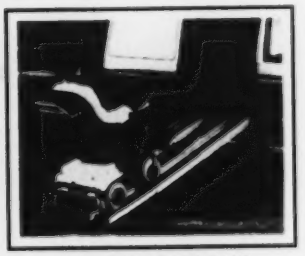

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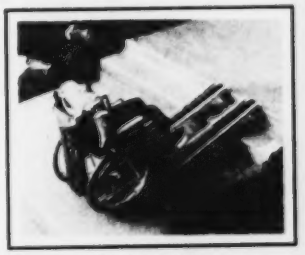

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length of his arm and the length of his stick in a strange environment. Your ears and senses are picking up everything around you, but you know that you're limited by the distance you can reach with your arm and the distance you can touch with that stick. And my parents saw that. "I watched while you asked the first three kids for help," my mom said. "You didn't get it. The kids gave you that kind of 'Oh, I don't know. Go ask somebody else.'"

Special Parent, Special Child

Special Parent, Special Child—a book that I am more proud of than any of my others—focuses on feelings all parents with children of disabilities share. When I first spoke about my childhood with my mother, I realized that although I had often been asked what my parents did when I was a child, no one had ever asked how they felt. After hearing my mother speak about her pain, I wanted to let other parents speak openly, to share all the feelings that no one had asked them about before. I interviewed more than 200 families and chose six that I felt could express their experiences with the most insight and eloquence. These families were wonderfully candid in discussing the strain of raising a child with a disability.

Speaking with them, it astounded me to learn that the pain and anguish felt by my parents 47 years ago has not been eliminated, but has only been made sharper by a more complex health system. It was no surprise to discover that parents have strengthened their love for their children and the resolve needed to help them succeed. Caring teachers and school administrators struggle to do a good job with less money and more students. Doctors love and nurture their patients and therapists give of themselves, but they are hampered by a complex and slow-moving health care system. In the end, the success of people like me comes from parents who do not accept "no" as an answer and who are creative, making the most of an environment that contains opportunities for every child with special needs. **EP**

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MEDIA

WHEN YOUNG CHILDREN ARE INJURED: FAMILIES AS CAREGIVERS IN HOSPITALS AND AT HOME by Marilyn Lash, M.S.W. and Jane Haltiwanger, M.A., Ed.M., is published by EXCEPTIONAL PARENT PRESS and is available through EXCEPTIONAL PARENT LIBRARY (800/535-1910). It is the third in a series developed by the Research and Training Center in Rehabilitation and Childhood Trauma, Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center. The following is an excerpt:

Parents and professionals sometimes disagree over whether it is helpful for parents to be with their child during a painful procedure. Some parents feel that there is no time when their support is needed more and prefer to stay with their child. Some professionals try to involve parents in specific ways to help calm, distract or reassure their child. Others believe that the anxiety and distress of parents can upset the child even more… Decisions must consider the child's age and ability to understand what is happening, a parent's reaction and ability to give comfort or reassurance and a professional's preferences and past experience…

Parents can help professionals during difficult procedures by avoiding negative comments so that the child does not see the professional as the "bad person who did this to me." Parents can help children build trust in caregivers by helping them understand that sometimes "it hurts for awhile."

Limits of parents' power

Young children believe that parents can do just about anything. They are used to being loved, fed, washed and entertained. It is a shock to discover that parents are unable to protect them from pain, take them out of their bandages or traction, or change other unpleasant parts of their hospital care. If parents choose not to be present during painful procedures, or if they are asked to leave, they still have an important role in comforting the child after the procedure is over.

An injured child needs help to sort out confusing messages about who is in charge, who to trust and what parents can and can't do. Toddlers or preschoolers may feel their trust in you has failed. They may be upset when your touch and smiles are not matched with the power to fix things as you have in the past. Build trust again by preparing your child for each new experience. When you pause to explain what will be happening, and it then happens the way you predicted, your child will be comforted and gain some security…

Pain and medication

It is very hard for parents to see their children in pain. Many parents feel especially helpless and worried when they must leave. You can help your child by following these suggestions:

- Ask doctors and nurses about the advantages and disadvantages of pain medications and their schedule and doses.
- Help your child during difficult times before medications take effect and when they are wearing off by reading stories, playing games or singing songs. Distraction can lessen pain.
- If your child has unpleasant side effects, such as nausea, confusion, agitation or sleeplessness, report them to the nursing staff or doctor. You and your child may fear that the condition is worsening when changes may be related to medication.
- Communicate for your child. Early signs of pain in facial expressions, sighs or moaning, or muscle spasms may be more readily noticed by you. By reporting them early to staff, you may be able to prevent pain from worsening.
- Discuss back-up plans about pain management and medication in advance. Even if not needed, knowledge of alternatives may help lessen your fears… **EP**

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Young bodies float in a broad expanse of bathtub warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex, laughter at splashes and water-antics, shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

For the boy in our picture above, the intense relaxation of the Hubbard Tank helps to maintain his range of movement. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more co-ordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young woman in the therapeutic pool also enjoys a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a moveable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the youngsters, when in the pool, to move in ways in which otherwise they cannot: when in the water they might walk independently, or might acquire real movement instead of spasticity. Here, in the supportive, liquid warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced, and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multifac ted program at Berkshire Meadows, a private, non-profit residential school or children and adolescents who are severely developmentally delayed and may be multiply disabled. Our program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of precognitive, cognitive, pre-vocational and independent living skills. We have an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.

For further information, please contact: Gail Charpentier, Executive Director, Berkshire Meadows, 249 North Plain Road, Housatonic, MA 01236 (413) 528-2523

SUMMER FUN!

And We Thought Planning Was the Key

by Nancy Sturm

We thought we were ready. We had stored a full case of youth-sized Attends in a roomy bin in the kitchen of our new RV. We had refilled prescriptions and carefully deposited 10 days' worth of meds in a high cupboard, out of the reach of toddlers. We had laid in a supply of Ensure for David and tapioca for Brenda—life without tapioca would have no meaning for Brenda. We had carefully stockpiled groceries for grownups, favorite treats for toddlers and foods that could be pureed for the non-chewers among us. We had a week's supply of bibs and we had clothing for any type of weather we might encounter. Yes, we were ready...

My husband Bruce and I are experienced campers. As the last of our five children left for college, the two of us continued to enjoy weekend and week-long wilderness treks. Our 17-foot canoe carried us and our minimal camping gear to remote and beautiful campsites.

Then, in 1990, the course of our life changed direction. We had volunteered to drive our daughter to Mexico, where she would spend a summer working at a church-operated orphanage for children with disabilities. There, in Northern Baja, we met eight-year-old Brenda. Meningitis at age two had left Brenda with cerebral palsy, a seizure disorder, hydrocephalus and profound mental retardation. After 14 trips to Mexico in a 14-month period, we adopted Brenda and brought her home to Oregon.

The next year, our foster son, David, now 13, came to live with us. David also has cerebral palsy, a seizure disorder, functional blindness, profound retardation and—depending on who's doing the assessment—autism or autistic-like behaviors. We weren't quite Ozzie and Harriet Nelson, but we now had the ideal American family—a boy and a girl!

Joining the full-hookup crowd

Even veteran campers like us, however, had to recognize that our days of canoe camping had come to an end. First, we replaced our 10-year-old Dodge minivan with an equally well-used Ford one ton—an immense, faded blue van with a lift for the wheelchairs and enough room for five adult passengers.

Next, we found an affordable RV, complete with air conditioning, forced-air heat, stereo, shower, toilet, microwave, VCR and full kitchen. With only the tiniest twinge of guilt, these camping purists had joined the full-hookup crowd.

(Above) **Sneaking a kiss:** Nancy and Brenda enjoy a relaxing afternoon at the campground. (Right), (From left) Abby's son, Cameron, 4, enjoys an evening around the campfire with Nancy, David, 12, Brenda, 8, and Bruce.

For the maiden voyage of our new RV, we invited our friend Abby and her family to join us, thinking we could share parenting duties so all of us would have a chance to do a little bike riding and hiking. Her husband couldn't get away from work, but Abby jumped at the chance to spend 10 days traveling with four-year-old Cameron and baby Harrison. We added their backpack, stroller and baby jogger to our wheelchairs on the list of essential camping gear.

We gave a copy of our well-planned itinerary, complete with campground phone numbers, to anyone who showed the slightest interest. We were so efficient in our trip planning that we managed to slip in a stop near Portland for a necessary cast change for Brenda, who'd had surgery on both feet a month earlier.

The first campground on our tour was Oregon's Jessie M. Honeyman State Park. Although we couldn't go up onto the dunes that are one of the favorite attractions of this beautiful park, we hiked along the miles of hilly paved paths with David in his wheelchair and Brenda in the baby jogger, which afforded more comfort for her casted legs.

Even a heavy rain the second night

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didn't dampen our spirits, and in the morning, we packed up as scheduled and drove north along Oregon's rugged central coast to Lincoln City, where we'd planned a shopping stop at a complex of the outlet stores. Bruce pulled the big van and even bigger RV side-by-side in the parking lot, Abby and I fixed lunch for everyone, then Bruce, David and Cameron napped while Brenda, Abby, Harrison and I shopped. We congratulated ourselves. This was the way to camp!

That night we camped at Champoeg State Park, a historic site on the Willamette River offering miles of paved hiking trails. Brenda, usually a good eater, didn't eat well and seemed a little grouchy. Since Abby and I were also feeling a bit grumpy after a long day in the van and a late arrival at our campsite, we weren't particularly concerned.

Our perfect plans unravel

The next morning's plan was for Abby and her boys to spend some time with a friend of their family while Bruce, David, Brenda and I ran up to Oregon Health Sciences University for Brenda's cast change. Brenda still seemed cranky and, once more, did not eat well. As we drove, she started to vomit profusely and became so limp she could not sit up.

WHAT HAD HAPPENED TO MY PERFECTLY PLANNED VACATION SCHEDULE? WHY, IF I NEEDED A VACATION AND HAD CAREFULLY PLANNED A VACATION, WAS I NOT GETTING A VACATION?

When we arrived at the doctor's office, Brenda's orthopedist proceeded with the cast change, but had his nurse call the chief of pediatric neurosurgery at University Hospital. By the time her casts were replaced, Brenda had been scheduled for a CAT scan and an evaluation in the neurosurgeon's office. By lunch time, she had been admitted to the hospital—ensconced in the very same room she'd occupied a month earlier—and shunt-revision surgery had been scheduled.

My head was swimming. *What* had happened to my perfectly planned vacation schedule? Why, if I *needed* a vacation and had carefully *planned* a vacation, was I not *getting* a vacation?

Unlikely coincidences

Like many Christians, Bruce and I believe that the course of our lives has been ordained by God. And as I sat beside Brenda's bed waiting for an operating room to open up, I began to realize how amazingly fortunate we had been. What an unlikely coincidence that

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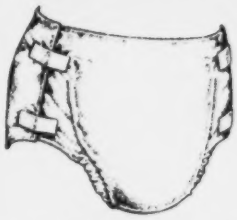

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David and Brenda look on as Bruce, with baby Harrison on his back, helps four-year-old Cameron with his archery.

Brenda's shunt should fail just as we were driving to the hospital; that the chief of pediatric neurosurgery, whose specialty is shunt revisions, was in and available; that Abby, with her experience in caring for children with disabilities, was with us; and that Bruce had a place to stay while Brenda was hospitalized. I thanked God for the way He had cared for us, but I had to sneak in just the tiniest request that next time, He provide an advance copy of His agenda.

I spent four days of our vacation living in a cramped room on a cot next to Brenda's bed talking quietly with the three other moms lying on similar cots next to the beds of their own daughters, reading whatever I could get my hands on, comforting Brenda and walking back and forth from the hospital cafeteria on the third floor to Brenda's room on the fourteenth.

Abby spent her vacation back at Champoeg State Park, caring for David and her own two boys, and Bruce shuttled back and forth between the hospital and the campground.

On Saturday, Brenda was released from the hospital, and we arrived home in Southern Oregon right on schedule.

Hitting the road again

Were our camping days over? Would Abby ever set foot in our van again? Should we just keep our kids at home where they are safe? We've answered a resounding "no" to all three questions. Since the inaugural voyage of our RV, we've managed several more outings without difficulties. Abby and her family joined us for a return trip to Champoeg State Park to visit the historic sites we had missed before. And we still feel that allowing Brenda and David varied experiences is more important than wrapping them in cotton wool.

Now we're planning a trip to Mexico for a visit with Brenda's old chums at the orphanage. But this time I'm bringing lots of extra reading material... because you just never know. **EP**

Nancy and Bruce Sturm live on a farm in Applegate, Oregon with their adopted daughter Brenda, 9, and foster son David, 13. The Sturms also have five grown children, and are hoping to adopt another child with a disability.

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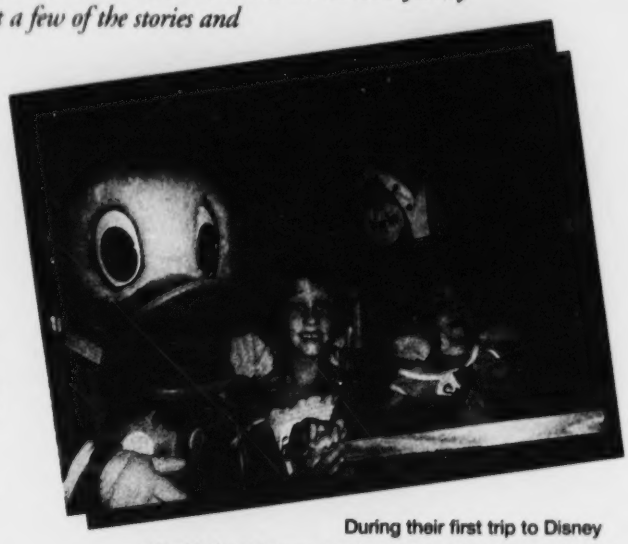
Circle #17

SUMMER FUN!

READERS TALK ABOUT: VACATION

A few months ago, we asked readers to tell us about memorable family vacations. Here are just a few of the stories and pictures they shared...

Careful Planning and a Positive Attitude



During their first trip to Disney World, the Williams children enjoyed breakfast with the Disney characters. Meeting Donald Duck are (clockwise from left rear) Will, 8, Kevin, 12, Sarah, 2, and Faith, 4.

My husband and I have never been able to agree on the perfect vacation. His ideal vacation is spent sitting quietly in a fishing boat on the Mississippi River. I, on the other hand, love to travel to distant and exciting places. Beginning when all four of our children were young, I began traveling with them by myself.

We took our first major vacation 10 years ago, traveling by train from Iowa to Disney World in Orlando, Florida. Sarah was two years old, Faith was four, Will was eight, and Kevin, who has Down syndrome, was 12.

The day before we left, Sarah was diagnosed as having "failure to thrive with swallowing dysfunction." We were advised to schedule surgery for a gastrostomy tube as soon as possible. To me, "as soon as possible" meant *after* our trip. For now, my mission would be to fatten Sarah up while having fun!

I quickly learned that Amtrak was not as accessible as I had been told. Only one car was wheelchair accessible. Because of this, I had to carry Sarah to the dining car; there were definite advantages to her being underweight!

Kevin wandered off several times, but you can only wander so far on a train. The porters became extremely protective of us—a sort of extended family for the duration of the trip.

I wanted to show the children our nation's capitol during a two-hour layover in Washington, D.C. The Amtrak staff was determined to keep passengers from leaving the train, so we sneaked off. We hailed a cab and told the driver we had $20 and one hour to see the town. We managed to see many of the sites and still get back to Union Station in plenty of time to reboard.

We had a wonderful week at Disney World. I occasionally left Sarah with a caregiver referred to us through the local Arc chapter. Kevin challenged us daily with his behavior, but I only lost him once—on our last day at the park. However, we all managed to find each other in time to return safely home.

Return to Disney World

Eight years later, we returned to Disney World; this time we drove. By then, Sarah had many more diagnoses including recurrent pancreatitus, seizures, osteogenesis imperfecta, reactive airway disease and gastrointestinal problems.

Our previous vacations had taught me the value of planning ahead. First, I had to think about Sarah's equipment—feeding pump, formula, bags, syringes for flushing the tube, an extra tube, diapers, underpads, suction machine and oxygen. I worked with our equipment company, Miller Medical in Coralville, Iowa. They gave me a list of other medical equipment suppliers in case we had a problem during our drive or stay in Orlando.

For our 20-day vacation, we needed 200 diapers and 120 cans of formula. Instead of trying to stuff these supplies into the van, we brought along only what we needed for our days on the road. A week before the trip, we shipped the rest to Florida. The packages were waiting for us upon our arrival.

One of my biggest worries was that Sarah would have a seizure and I would not be able to find her medicine. I put a supply into the overnight bag we used while on the road. I put more in her wheelchair bag, my purse and our lug-

continued on page 34

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT. In upcoming months, readers will be talking about:

- **helping a child make friends (July; deadline May 1, 1995)**
- **experiences with genetic counseling (August; deadline June 1, 1995)**
- **educational options—special schools or inclusion (September; deadline July 1, 1995)**

Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).*

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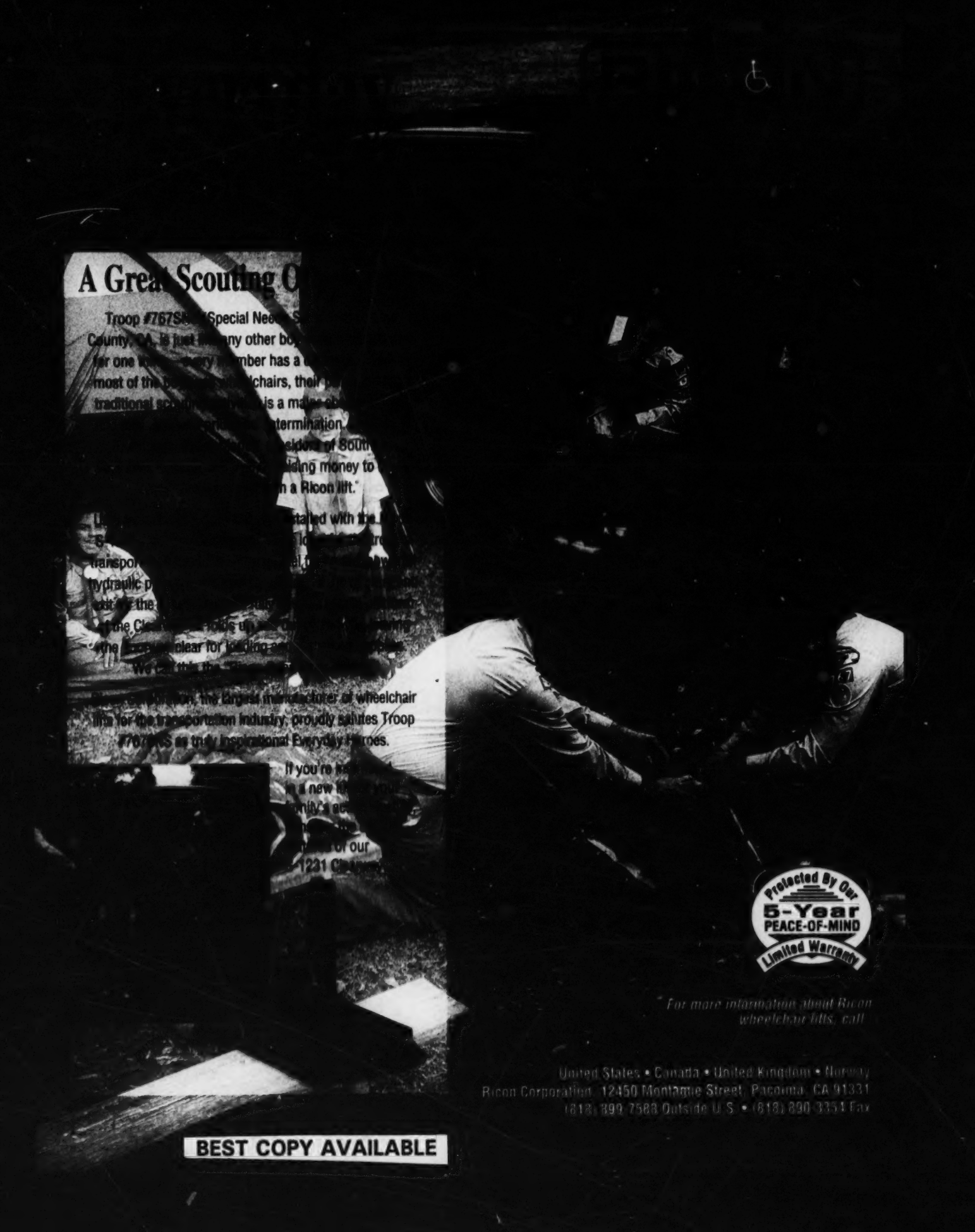


BEST COPY AVAILABLE

Careful Planning and a Positive Attitude

continued from page 32

gage. I also brought along the original prescriptions of her medications and another for antibiotics in case she got a simple ear infection or strep throat.

I found affordable accommodations at Disney World's Polynesian Resort. Although we paid more for being on-site, it was worth it. We were on the monorail line so all the kids, including Sarah, could come and go easily.

Our insurance company found a nurse for Sarah and paid for one visit a day. This not only gave me a much-needed break, but would also have provided a medical referral if Sarah had needed a doctor.

Sarah celebrated her tenth birthday with Mickey and Minnie and ended up with four complimentary birthday cakes. She couldn't eat a bite, but the rest of us did!

To deal with Kevin's challenging behaviors, I had made behavior management charts with rewards for positive behavior. In the end, however, letting him experience the natural consequences of his actions proved more effective. One day, for example, Kevin refused to wear shoes. Then, he decided he could not walk on the hot sidewalk. Faith tried to get him to come along with her, but he was an immovable object, so he missed dinner—an important meal to Kevin.

This summer, I am taking Sarah, Faith and a friend on another trip. I feel sad when I hear families say, "We couldn't possibly take Johnny anywhere, so we all stay home." With careful planning and a positive attitude, anything is possible.

–Mindy Williams
Tipton, Iowa

Ready to go: With his carseat secured at one end of the canoe, 22-month-old Jeremy appears eager to travel.

Due North

My husband, Lawrence, and I have gone wilderness camping by canoe since the beginning of our marriage; when our children were born, it seemed natural to include them in these trips. Our two older children were "on the water" before each was 18 months old. When our third child, Jeremy, arrived, we didn't hesitate to take him along, too. However, Jeremy was born with developmental delays, hypotonia, nystagmus, kidney disease and slow growth. In planning for any trip, we knew we would need to balance his safety with our fun.

We decided that a short trip within safe distance of a major hospital would satisfy both needs. Over Labor Day weekend in 1993, we camped at the Algonquin Provincial Park, 350 miles due north of Toronto, Ontario. Jeremy was 22 months old; Jonathan and Ashley were 11 and 9.

Wilderness camping means being completely dependent on the contents of your canoe. We planned extra carefully to be sure we didn't forget any of Jeremy's medications, formula or food. We chose our destination to be within eight hours travel of Toronto Children's Hospital. Jeremy's nephrologist had called the kidney specialists there to let them know about Jeremy in case he had an emergency.

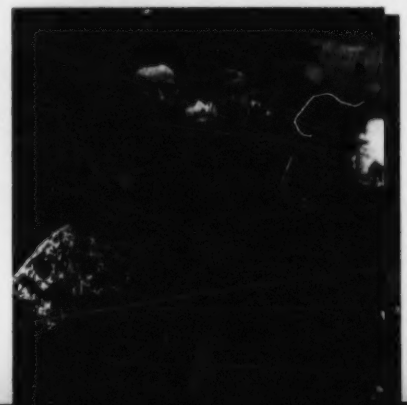
After driving to the park, we paddled 10 miles on the lake to a rustic, unimproved campsite. Jeremy wore a life vest and sat in his car seat, which we lashed to the thwart (horizontal support) of the canoe. He really enjoyed the movement of the waves and watching the loons and ducks floating on the water. Our biggest problem was keeping him from leaning over the edge of the canoe to run his fingers in the water. His big brother had to steady him several times to keep him balanced in the boat.

At the campsite, we put up the tent. Jeremy used his own "Mickey Mouse" sleeping bag and, after one restless night, slept soundly. We had to pack in clean diapers and pack out dirty ones. We did diaper changes on a changing pad laid out on the ground. Cooking was done over a campfire or portable camp stove. Cleaning out baby bottles was a bit of a chore. We drew water from the lake and boiled it to wash bottles and dishes. Food was put into duffel bags and hung high on tree branches to keep bears and raccoons from eating it.

Jeremy thrived on the constant attention he received. Without the distractions of television, radio, school, therapy visits and doctor's appointments, our family had only each other for entertainment. We did a lot of talking, singing, working and fishing together. Though severely delayed in verbal skills, Jeremy added several words to his vocabulary during the trip. He was very inquisitive about his surroundings and explored by crawling around the campsite on his hands and knees—much to Mom's dismay when she did the laundry at home!

The extra work and planning were well worth having Jeremy along. His enthusiasm and curiosity helped us all re-experience the awe and wonder of our first trips into the unspoiled wilderness. We can't imagine life or a vacation without him.

–Paulette Gaia
Chesterland, Ohio



With Jeremy on his back, Lawrence Gaia enjoys a wilderness hike with children Ashley, 9, and Jonathan, 11.

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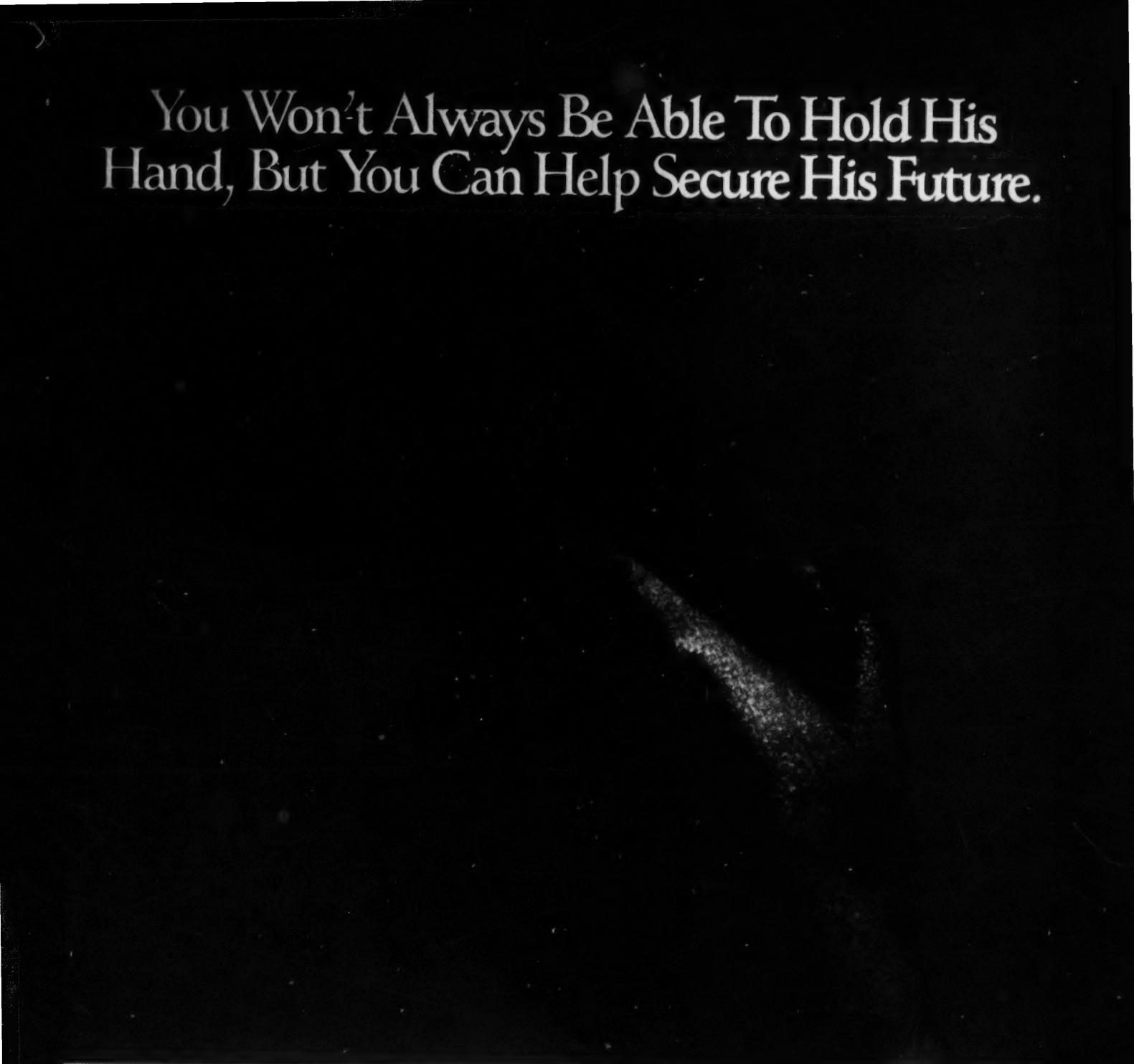

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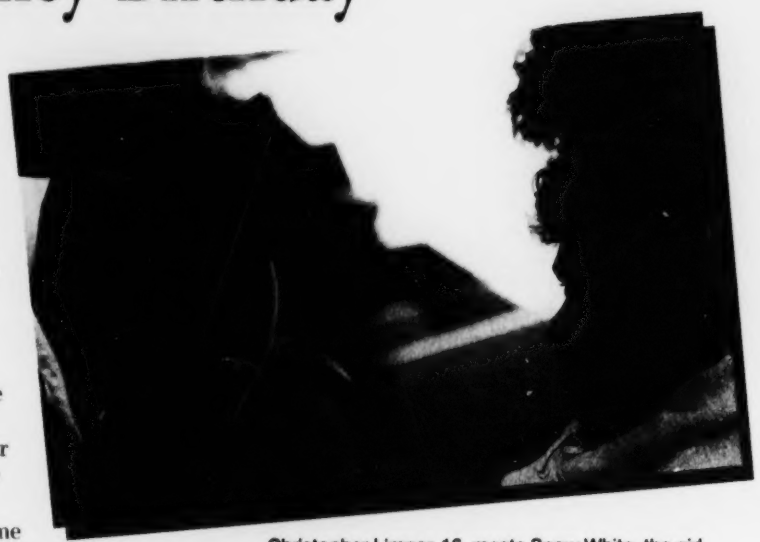
SUMMER FUN!

A Disney Birthday



Christopher Limpar, 16, meets Snow White, the girl of his dreams.

Our planning for Christopher's sixteenth birthday began when he turned 15. Christopher's disabilities include cerebral palsy, a seizure disorder and profound mental retardation. He does not speak or walk independently. Christopher lives in an intermediate care facility and makes frequent home visits.

We (Christopher's mom, Glynnis Rea, and myself, his godmother) wanted Chris to celebrate his sixteenth birthday in a world we knew was special for him. We spent a year preparing him for the birthday celebration he would have at Disney World in Orlando, Florida.

The highlight of Chris' birthday celebration came in Fantasyland at the Magic Kingdom where he met the girl of his dreams—Snow White. The Snow White story has long been one of his favorites, and we told Chris he would meet her at Disney World.

Chris can walk with assistance, but does not have the ability to stand alone. But when he saw Snow White, Chris indicated that he wanted to get out of his wheelchair. With help, he walked over to Snow White and beamed as she was introduced to him. She talked to Chris for several minutes, then kissed him on the cheek. Wow! What a birthday!

The accommodations at Disney's All-Star Music Resort were wonderful. Our room had an accessible bathroom and was within walking distance of a food court, gift shop, game room and swimming pool. Wheelchair-accessible shuttle buses to and from the theme parks ran every 20 minutes. The attentiveness of Disney employees to our needs made our vacation even more memorable.

The First Aid and Baby Care Stations at each of the theme parks (Epcot, MGM Studios and the Magic Kingdom) were invaluable. They were equipped with private rooms and kitchens with microwave ovens where we were able to prepare Chris' puréed diet, feed him and attend to his personal needs.

We didn't realize how much stamina Chris had until the Disney trip. We arrived at the parks around 10 each morning and usually stayed until closing. Chris especially enjoyed Epcot Center where he rode Spaceship Earth, the Journey into Imagination, the Universe of Energy and many more rides. At the World Showcase he ate his birthday dinner in Mexico, had dessert in France and did his souvenir shopping in Canada.

Our success was definitely due to the planning we did and the time we took to prepare Christopher for his magical adventure.

–Alice E. Mudge

Alice Mudge lives in Germantown, Pennsylvania. Christopher's mother, Glynnis Rea, also contributed to the writing of this story.

Preparation is Key

Although our planning was specific to Disney World, similar strategies could be used by families planning other trips:

- Disney World's free *Guidebook for Guests With Disabilities* provides an overview of special services and accessible facilities, particularly for individuals using wheelchairs. Our copy of the *Guidebook* helped us plan more effectively.
- We familiarized Chris with the theme parks he would be visiting by having him watch a vacation planning video about Disney World during his home visits.
- Chris listened to audiotapes featuring Disney characters he was likely to meet and music he was likely to hear.
- The day before we left, we brought Chris to the airport to watch planes taking off and landing. We explained boarding procedures to him.
- We worked closely with a travel agent to ensure that our needs were met. We booked seats close to the plane's door for ease in getting Chris on and off the plane. His wheelchair was "gate-checked" and put in the cargo section of the plane. A crew member brought it to the door of the plane immediately after landing.
- We requested accessible accommodations at Disney's hotels and asked specific questions prior to making a reservation to ensure that the room would accommodate our needs.
- We brought extra medication with us on the plane in case of delays.
- Timing was crucial. We made the trip in February because Chris does not tolerate extreme heat.

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Circle # 133

SUMMER FUN!

An afternoon on the lake: (From left) Jonathan Moran, Theresa Moran, Daniel Hawkins, Mathew Moran and James Moran enjoy canoeing at Camp Glen Spey.

Family Camping

For the last five years, we have gone on an annual camping trip with several other families. When we invited these other families to share our first family camping trip to Camp Glen Spey, a Girl Scout camp in Glen Spey, New York, most had not been camping before.

These were people that we knew well. We knew their standards of behavior for themselves and their children. We knew that they were tolerant of our children and that we were tolerant of theirs.

On that first trip, eight adults and 13 children, aged two to 14, spent at least part of a five-day period at the camp. Four of the children had disabilities, including attention deficit hyperactivity disorder (ADHD), learning disabilities, low vision and arthritis. Each child had at least one friend his or her own age, which the children said was one the best things about the trip.

A week before the trip, we had an organizational meeting to outline procedures, rules and routines. We talked about the chores each person would do and planned meals, taking special dietary needs into consideration.

We chose to stay in a large cabin instead of tents. This made it easier to store food and medication. The cabin was no more than 200 yards from anywhere we needed to go. It had a main room with 20 cots, several tables and chairs, a wood stove and a fireplace. There was a phone connected to the site director's lodge and the ranger's house. We parked our cars next to the cabin so they would be available in case of an emergency.

Since we had no fewer than five adults at camp at any time, we were able to supervise all the activities at one time. The children were required to use the buddy system; no one could be alone at any time. As long as they were with their buddies, however, they could go to any activity site where there was an adult. The children could spend as much time as they wanted at each activity.

Although closely supervised, the children felt independent. All the adults shared child care—and we even got some precious time to ourselves. The teens also helped to supervise smaller children; they understood that safety was everyone's responsibility.

The waterfront offered swimming, rowboats, canoes, kayaks, inner tubes and sailboats under the supervision of a certified water safety instructor.

We did have to adapt some activities for our children. For example, Jon and Matt were not strong enough to paddle the kayaks. However, with the kayak tethered and an adult nearby, we let them ride in and paddle the kayaks just outside the wading area.

We went on a hike and had a scavenger hunt. Instead of collecting things during the hunt, we used our senses to explore the woods—the textures, sounds, smells and sights. The hike was purposely short and ended at a gravel path so we could have a car available for those who were too tired to walk back to the cabin.

After each night's dinner, we lit a campfire. We sang and told stories—but no ghost stories! As each child fell asleep, we carried them into the cabin and put them to bed. The older children stayed up later. Once they were also in bed, the adults had some quiet time to themselves under a starry sky within a few feet of the sleeping children.

These trips have been our family's favorite and most relaxing vacations. Sharing chores, especially child care, makes it possible to have some much-needed time off. The slow pace, flexible schedule and choice of activities have made these trips successful.

–Theresa and James Moran
Ridgewood, New Jersey

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Surf's Up!

Brian loves the beach. With a PVC-pipe beach buggy we have made ourselves, Brian is able to enjoy walks on the beach and getting splashed by the waves.

Brian, 11, has lissencephaly and cerebral palsy. He is unable to sit or stand unsupported. Brian uses a custom-built wheelchair that provides lateral and head support.

We started building equipment for Brian years ago when we could not find certain equipment, or when the commercial alternatives were too expensive. One of our most successful early projects was an "all-terrain vehicle." We started by building a PVC-pipe chair frame modeled after the seat portion of his wheelchair. The chair's back and seat were made of plywood, cushioned with foam and covered in canvas. We bolted it into a Little Tikes plastic wagon with wide wheels that went well over gravel, dirt and grass.

Best of all, we discovered that our home-built vehicle also rolled along great on a sandy beach! We started taking vacations in Cape May at the New Jersey shore where we eventually bought a summer home. Many of the Cape May beaches are accessible—ramped down to the sand. (Several adult-size beach wheelchairs are also available and might be useable by children with good trunk control.)

Mom Helen and "beach bum" Brian enjoy the beach at North Cape May, New Jersey.

After five years, Brian outgrew this first wagon. That is when we made our newest beach buggy. It was a family project with Brian assisting from his prone stander, now re-named "Brian's workbench." The new buggy has an all-PVC frame with large, fat, garden-cart tires. The seat, back and footrest are made from the same kind of vinyl-coated nylon webbing that is used for lawn furniture. The chair comes off the wheel base so Brian can also use it around the house.

The best feature of this beach buggy is that it is completely waterproof. We can walk the buggy right into the water and let the waves splash over us. Brian likes to "jump waves" with his dad.

Brian always smiles when someone stops us to ask about his buggy. He is proud that he helped to build it, and he really likes being able to enjoy so many once-inaccessible places.

–Helen and Joe Markee
Franklin, Massachusetts

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Circle # 151

Sharing the World with Our Children

Our two-year-old son's diagnosis with a rare disorder sent us into a tailspin—surgeries, specialists on both coasts and trying to make sense of all the changes this diagnosis meant for Ezra, for the two of us and for the rest of our family.

Through it all, we held on to a very strong desire to travel again. Traveling had been an important part of our marriage and we did not want to lose all sense of our previous life. We found the answer in cruises.

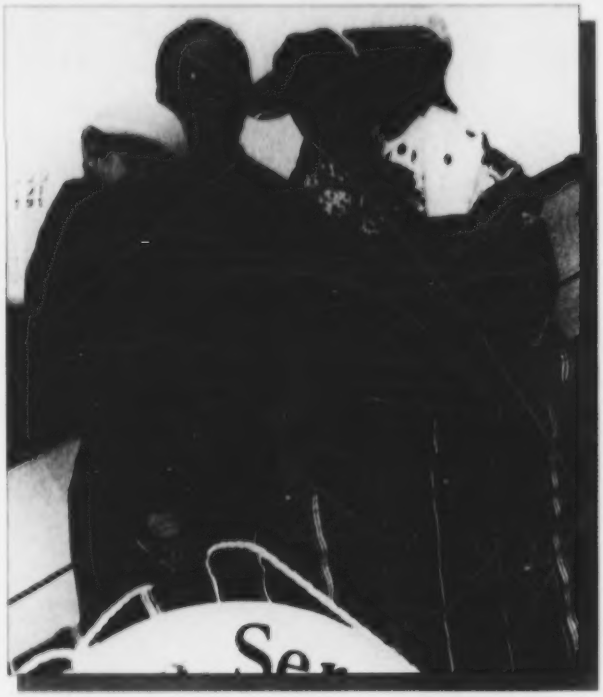
Both our son and daughter have disabilities. Ezra, now 5, has familial dysautonomia (FD), a genetic disease occurring primarily in Jews. FD causes dysfunction of the autonomic nervous system, which controls such bodily functions as blood pressure, body temperature, swallowing and digestion. The condition also affects sensory abilities. Individuals with FD may have a decreased or absent reaction to pain and a lack of taste buds. Unrelated to FD, both Ezra and Eliana, 8, also have a deletion of the short arm of the eighth chromosome.

When planning a cruise, we always have our travel agent inform the cruise line about our family's special needs. This prepares them to make accommodations. When we arrive at the dock, the ship's staff is waiting to help us carry Ezra's medical equipment onto the ship. They always make sure we can board immediately and do not have to wait in line for documents.

Dietary needs are a constant concern for us. Eliana is highly allergic to all dairy products. Ezra is fed every night by a gastrostomy tube; he can eat some food, but rarely drinks by mouth. Shortly after boarding a ship, we give the head chef a detailed list of the foods our children can and cannot have. Kitchen staffs have been very accommodating in meeting our children's special food needs and have always made food available if a meal is missed or medical needs interfere.

Cruise ships always sail with a full medical staff. We make sure we meet the doctor and know the location of the ship's medical center. Fortunately, we have needed medical attention only once.

Ezra participates in all the activities planned for kids—even if that means joining a group of slightly younger children in order to keep up and be able to rest when he gets tired.



All aboard! Gary and Georgia Freedman-Harvey, with children Eliana, 7, and Ezra, 4, board the cruise ship Viking Serenade during a 1993 family vacation.

During our last cruise, Ezra and Eliana were determined to enter the talent show. Even though Ezra was just learning to sing, and only sang every other word, our kids were the stars of the show. They received medals and lots of applause; Ezra's pride lasted for weeks.

A cruise ship offers plenty of room for moving around. When Ezra isn't feeling well, we push him in his cruiser to a spot on deck where things are happening. That way he still feels that he is part of the action. During visits to various ports, one of us can always return to the ship with Ezra, while the other continues sightseeing with Eliana. Neither of us ever feels like we are stuck in a hotel room at any time.

We look forward to going on longer cruises with our children. It is one way we can let our son see the world and participate in the fun of travel. Travel is an important part of the way we educate and have fun with our children. While we may not be able to travel to the most exotic and isolated spots, we can still share the world with our children.

–Georgia and Gary Freedman-Harvey
Seal Beach, California

Eliana and Ezra clown around with dining room waiter David.

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Travel Resources

SUMMER FUN!

Organizations

Mobility International USA
Mobility International USA (MIUSA) is a non-profit organization dedicated to equal opportunities for persons with disabilities in international educational exchange, leadership development, disability rights training, travel and community service. Since 1981, MIUSA has offered international educational exchanges for individuals with and without disabilities—including teenagers—from more than 20 countries. Program participants take part in leadership training, disability rights awareness, cross-cultural education and language classes. Applications are now being accepted for upcoming 1995 exchanges in Azerbaijan, Mexico, Russia and Eugene, Oregon. MIUSA publications include *A New Manual for Integrating Persons with Disabilities into International Exchange Programs* ($16 for MIUSA members, $18 for non-members; includes shipping) and *A World of Options for the 90's: A Guide to International Educational Exchange, Community Service and Travel for Persons with Disabilities* ($14 for MIUSA members, $16 for non-members; includes shipping). MIUSA also offers videos, a quarterly newsletter, *Over the Rainbow*, and travel information for members. To join MIUSA, or for an exchange application, contact P.O. Box 10767, Eugene, OR 97440, (503) 343-1284 (V/TTY), (503) 343-6812 (fax).

Travelin' Talk
Founded by Rick Crowder, an Air Force veteran with a disability, Travelin' Talk is a network of people and organizations who are willing to provide travelers with disabilities with information before and during their trips. Travelin' Talk spans the globe with resources, offers of help and information people with disabilities may need—all available over the telephone. A complete listing of members, the information they can offer and their phone numbers is compiled in *The Travelin' Talk Directory*, available through *Exceptional Parent Library*, (800) 535-1910; $32.50. Travelin' Talk also publishes a quarterly newsletter that includes updates of the member list, new travel resources, travel tips and stories about the ways members are helping travelers with disabilities. Subscriptions are available with any size donation to Travelin' Talk. Other services include listings of resources such as van rentals, accessible lodging, travel/tour agencies specifically for persons with disabilities and other organizations who can help travelers. For more information, contact Travelin' Talk, P.O. Box 3534, Clarksville, TN 37043, (615) 552-6670 (voice), (615) 552-1182 (fax).

Publications

Books

Able to Travel: True Stories by and for People with Disabilities
Edited by Alison Walsh with Jodi Abbott and Peg L. Smith; Rough Guides, Ltd. (1994)
More than 100 articles by travelers with various disabilities. Information on transportation, food, lodging, costs, and attractions from Amsterdam to Zimbabwe. Organized by country. 603 pp.
• **Available in the U.S. from:** Penguin Books, 37 Hudson St, New York, NY 10014, (212) 366-2000 (voice); $21.95 (includes shipping).

ACCESS Travel U.S.A.
Creative Hospitality Concepts (1994)
Quick-reference book, easy-to-use chart format. More than 800 listings of cruise ships, hotels and resorts, information and organization resources, ski areas and transportation providers; national directory of TTY numbers. Each listing features accessibility data including number of adapted rooms/cabins, automatic doors and elevators; room, bath, shower and door dimensions; and dining and public facility information including table height and Braille menu availability. 176 pp.
• **Available from:** *Exceptional Parent Library*, (800) 535-1910; $19.95.

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Everest Jennings

Circle #207

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FODOR'S GREAT AMERICAN VACATIONS FOR TRAVELERS WITH DISABILITIES
Fodor's Travel Publications (1994)
Guide to cities, parks and campgrounds for travelers with mobility, hearing and vision impairments. Very detailed accessibility information for restaurants, hotels and attractions. 600 pp.
• **Available from:** *Exceptional Parent Library,* (800) 535-1910; $18.00.

HANDICAPPED IN WALT DISNEY WORLD: A GUIDE FOR EVERYONE
By Peter Smith; SouthPark Publishing (1993)
Focus on mobility, but also addresses other disabilities and special health care needs. Includes travel options to and within Orlando; planning tips; detailed descriptions of hotels, airlines, rides and costs; maps. Resources arranged by specific disability. 293 pp.
• **Available from:** SouthPark Publishing Group, 4041 W Wheatland Rd, Ste 156-359, Dallas, TX 75237, (800) 669-5657, (214) 296-4686 (fax); $13.95 (includes shipping).

WHEELS & WAVES: CRUISE, FERRY, RIVER & CANAL BARGE GUIDE FOR THE PHYSICALLY HANDICAPPED
By Genie and George Aroyan; Wheels Aweigh Publishing Company (1993)
Individual passenger vessels are described in terms of wheelchair accessibility, diagrams and deck plans; organized by type of boat and region of the world. Includes tips on sailing, canoeing and rafting; local resources; and ADA regulations related to water travel. 173 pp.
• **Available from:** Wheels Aweigh, 17105 San Carlos Blvd, Ste A-6107, Ft Myers Beach, FL 33931; $11 (includes shipping).

Newsletters

THE DIABETIC TRAVELER
Quarterly. Each issue focuses on a different topic.
• **Diabetic Traveler,** PO Box 8223-RW, Stamford, CT 06905, (203) 327-5832, $18.95/year.

HANDICAPPED TRAVEL NEWSLETTER
Bi-monthly. All aspects of travel.
• **Handicapped Travel Newsletter,** PO Drawer 269, Athens, TX 75751, (903) 677-1260 (voice/fax), $10/year.

OVER THE RAINBOW *See: Mobility International USA under Organizations.*

TIDE'S IN
Quarterly newsletter of Travel Industry and Disabled Exchange (TIDE). Information on international accessibility, transportation, hotel accommodations and national and international tours.
• **TIDE,** 5435 Donna Ave, Tarzana, CA 91356, (818) 343-6339; $15/year.

TRAVELIN' TALK NEWSLETTER *See: Travelin' Talk under Organizations.*

Other Publications

ACCESS TRAVEL: AIRPORTS
Contains charts on accessibility features of individual airports in all parts of the world. Published 1993. Free.

NEW HORIZONS FOR THE AIR TRAVELER WITH A DISABILITY
Explains rules and guidelines governing airline travel and airport accessibility. 33-page booklet; 50¢.
• **Available from:** Consumer Information Ctr, Dept 3898, Pueblo, CO 81009, (202) 501-1794.

TIPS FOR TRAVELING WITH DISABILITIES
Travel tips and listings for tours, travel agencies and resources for travel information (including many large-print books and books on tape). Focus on U.S. 30 pp.
• **Available from:** Information Ctr for Individuals With Disabilities, 27-43 Wormwood St, Boston, MA 02210, (800) 462-5015 (V/TTY; MA only), (617) 727-5540, (617) 345-9743 (TTY), $10 (includes shipping).

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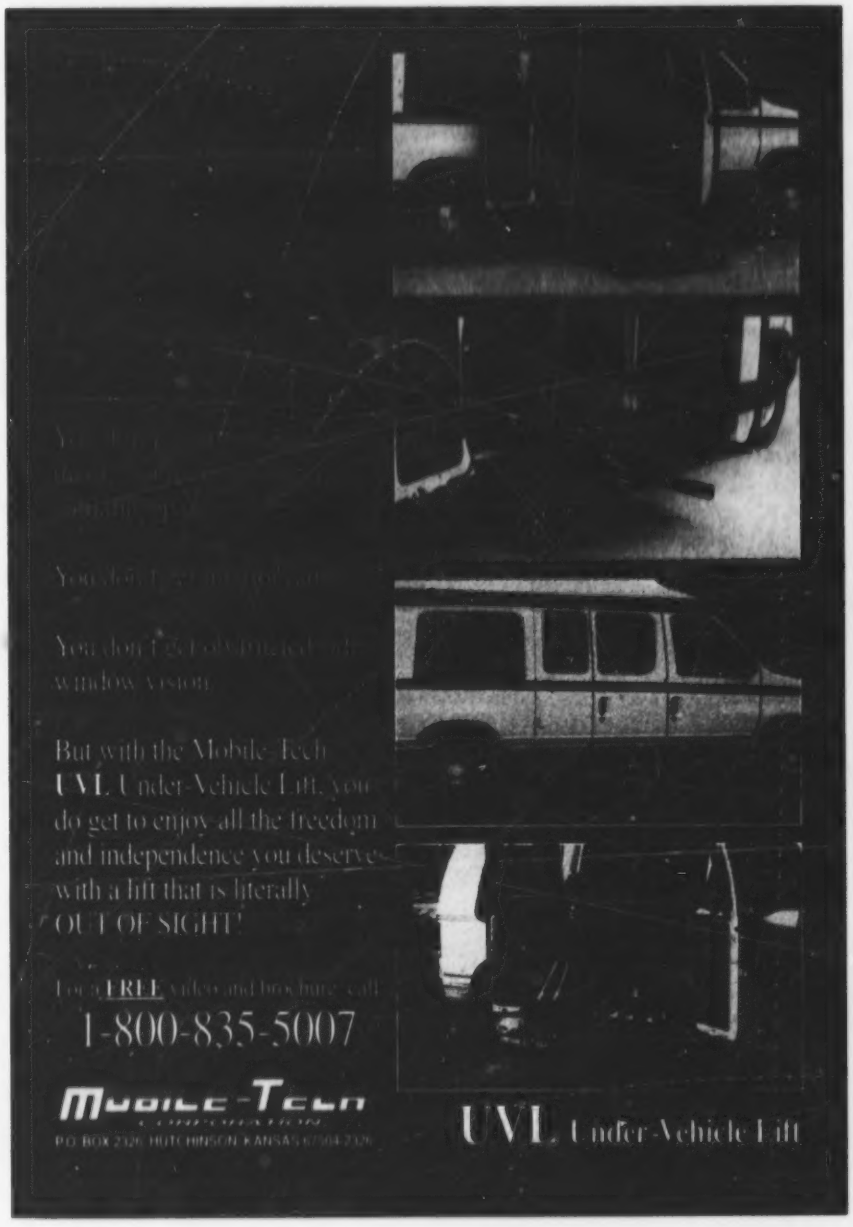
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Circle #69

TRAVEL RESOURCES

Hotels and Motels

Major hotel and motel chains can provide information about accessibility at individual properties. Most will also send free brochures with accessibility information.

Adam's Mark: (800) 444-2326

Best Western: (800) 528-1234 (voice), (800) 528-2222 (TTY)

Budget Host Inns: (800) 283-4678

Clarion: (800) 252-7466, (800) 228 3323 (TTY)

Colony: (800) 777-1700

Comfort: (800) 228-5150, (800) 228-3323 (TTY)

Compri: (800) 426-6774, (800) 528-9898 (TTY)

Days Inn: (800) 325-2525, (800) 325-3297 (TTY)

Doubletree: (800) 528-0444 , (800) 528-9898 (TTY)

Econo Lodge: (800) 446-6900, (800) 228-3323 (TTY)

Embassy Suites: (800) 362-2779, (800) 458-4708 (TTY)

Fairfield Inn: (800) 228-2800, (800) 228-7014 (TTY)

Forte: (800) 225-5843

Four Seasons: (800) 332-3442

Friendship Inns: (800) 453-4511, (800) 228-3323 (TTY)

Hilton: (800) 445-8667, (800) 368-1133 (TTY)

Holiday Inn: (800) 465-4329, (800) 238-5544 (TTY)

Hyatt Hotels & Resorts: (800) 233-1234, (800) 228-9548 (TTY)

Inter-Continental: (800) 327-0200

Accessibility at some Holiday Inn hotels include wide doorways and roll-in showers. Pictured is Holiday Inn's Crowne Plaza Ravinia in Atlanta, Georgia.

Photo courtesy Embassy Suites.

La Quinta: (800) 531-5900, (800) 426-3101 (TTY)

Leading Hotels of the World: (800) 223-6800

Marriott: (800) 228-9290, (800) 228-7014 (TTY)

Meridien: (800) 543-4300, (800) 441-2344 (TTY)

Motel 6: (505) 891-6161, (505) 891-6160 (TTY)

Nikko International: (800) 645-5687, (800) 255-2880 (TTY)

Omni: (800) 843-6664

Quality Inn: (800) 228-5151, (800) 228-3323 (TTY)

Radisson: (800) 333-3333

Ramada: (602) 389-3800 , (800) 228-3232 (TTY)

Red Lion: (800) 547-8010

Red Roof Inns: (800) 843-7663, (800) 843-9999 (TTY)

Ritz-Carlton: (800) 241-3333

Rodeway: (800) 228-2000, (800) 228-3323 (TTY)

Sheraton: (800) 325-3535, (800) 325-1717 (TTY)

Sleep Inn: (800) 221-2222, (800) 228-3323 (TTY)

Stouffer: (800) 468-3571, (800) 833-4747 (TTY)

Super 8: (800) 848-8888, (800) 533-6634 (TTY)

Travelodge: (800) 578-7878

Westin Hotels & Resorts: (800) 228-3000, (800) 221-8818 (TTY)

Wyndham Hotels & Resorts: (800) 822-4200 , (800) 441-2344 (TTY)

Van Rentals

While vacationing, many families need to rent wheelchair-accessible vans or automobiles that are large enough to accommodate needed equipment.

Some national car rental companies can provide accessible vehicles in some locations, but two leading rental companies specialize in vehicle rentals for people with disabilities:

Photo courtesy Wheelers Accessible Van Rentals, Glendale, AZ.

• **Wheelchair Getaways:** More than 85 locations throughout the U.S. and Puerto Rico. Offers full-size vans with wheelchair lifts or ramps, tie-down systems, raised roof or lowered floors and seating for up to four other passengers. Mini-vans and electric scooters available at some locations. Some vans equipped with hand controls.

Wheelchair Getaways, P.O. Box 605, Versailles, KY 40383, (800) 642-2042, (606) 873-8039 (fax)

continued on page 46

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Epilepsy Foundation
of America.

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Landover, MD 20785

(301) 459-3700 or
(301) 577-9056 (FAX)

Membership Reservation Form

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❑ Please charge my: ❑ VISA ❑ MasterCard ❑ American Express

Card No, _____ Exp. Date _____

Signature _____

Name _____

Address _____

City _____ State _____ ZIP _____

TRAVEL RESOURCES

continued from page 44

Photo courtesy Wheelchair Getaways, Versailles, KY

• Wheelers Accessible Van Rentals:
73 locations throughout the U.S. Offers accessible Chrysler mini-vans with lowered floors and automatic tuck-away ramps with seating for two wheelchair users and five other passengers. Electric scooters available. All vans can be equipped with hand controls if needed.

Wheelers Accessible Van Rentals, 7101 N. 55th Ave., Glendale, AZ 85304, (800) 456-1371, (602) 435-9989 (fax)

Call rental companies several weeks in advance to make sure they have what you need. Company representatives in many locations can provide information about local attractions and accessible accommodations. They may also provide advice on packing wheelchairs and other equipment for air travel.

—Marc S. Malkin

The Ultimate Playground: Amusement Parks

by Donna G. Albrecht

Abby Albrecht, 4, meets Mickey Mouse during a 1979 visit to Walt Disney World in Florida.

Certainly the ultimate playground is an amusement park because it combines all types of sensory stimulation. Whatever your child's level of physical ability, there will be new sights, sounds, smells and sensations to thrill her. Many parks have active attractions like rides and more passive attractions like stage shows. Plan to keep a balance so neither you nor your child become overly exhausted.

If you have any questions about whether a particular ride is safe and appropriate, ride it alone once to determine if it is safe for your child. For instance, a ride that exerts strong "G" forces as it swings in circles may cause you to slide on the seat. Ascertain if you can hold your child safely without her slipping or getting a body slam from you as you slide.

For children who are physically weak, the safest rides are normally the ones that do not need safety restraints, such as merry-go-rounds and any ride where you are completely enclosed in a seating container that moves gently. If you are considering taking your child on a thrill ride such as a roller coaster, talk with your doctor or physical therapist first and, if you must make an immediate decision, err on the side of caution.

Avoiding lines

Many parks have special entrances to rides and attractions for families with a child who has a disability. Often you can bypass the long lines and be accommodated almost immediately. However, some parks now have a policy that only one person may accompany the child. Others have to go through the line and you will all be accommodated when they reach the front of the line. In theory, it makes sense, but it can be pretty boring for the person who spends most of the day alone standing in line. Check with the park about its regulations before you go.

Meeting restroom needs

In all likelihood, the park will have some extra-large restroom stalls marked for people who have disabilities. However, if your particular equipment and maneuvering needs do not permit you to use these stalls discreetly, help is usually available. Look for a nursing or first-aid station. It should have a bathroom and/or private area with beds and bedpans where you can help your child with her toileting needs. The staff may be willing to lend a hand if you need help.

Excerpted with permission from RAISING A CHILD WHO HAS A PHYSICAL DISABILITY by Donna G. Albrecht (John Wiley & Sons, Inc., 1995); available through EXCEPTIONAL PARENT LIBRARY, (800) 535-1910; $12.95.

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Circle #215

TRAVEL RESOURCES

SUMMER FUN!

Theme Parks

Many theme parks offer free detailed guidebooks for visitors with disabilities. Some also offer discounts for visitors with disabilities. Accessibility services provided by each theme park are coded by number and follow each listing. Numbers correspond to items listed in the Key to Services.

Adventure Island
PO Box 9158
Tampa Bay, FL 33674
(813) 987-5600 (voice)
(813) 987-5443 (fax)
1,3,5,6,7,12,13

Busch Gardens Tampa Bay
PO Box 9158
Tampa Bay, FL 33674
(813) 987-5000 (voice)
(813) 987-5443 (fax)
1,3,5,6,7,12,13

Busch Gardens Williamsburg
1 Busch Gardens Blvd
Williamsburg, VA 23187-8785
(804) 253-3350 (voice)
(804) 253-3399 (fax)
1,2,3,5,6,7,12,13

Disneyland
c/o Information
1313 Harbor Blvd
Anaheim, CA 92803
(714) 999-4565 (voice)
(714) 999-4569 (TTY)
(714) 490-3223 (fax)
1,2,3,4,5,6,7,8,12

Hersheypark
100 West Hersheypark Dr
Hershey, PA 17033
(717) 534-3900 (voice)
(717) 534-3830 (TTY)
(717) 534-3165 (fax)
1,2,3,4,5,6,7,10,12,13

Oceans of Fun/Worlds of Fun
4545 Worlds of Fun Ave
Kansas City, MO 64161
(816) 454-4545 (voice)
(816) 454-4655 (fax)
1,2,3,5,6,7,12,13

Sea World of California
1720 South Shores Rd
San Diego, CA 92109
(619) 226-3929 (voice)
(619) 226-3953 (fax)
1,2,3,5,6,7,8,12,13

Sea World of Florida
7007 Sea World Dr
Orlando, FL 32821
(407) 351-3600 (voice)
(407) 345-5268 (fax)
1,2,3,6,7,8,9,12,13

Sea World of Ohio
1100 Sea World Dr
Aurora, OH 44202
(216) 562-8101 (voice)
(216) 995-2185 (TTY)
(216) 995-2119 (fax)
1,2,3,4,5,6,7,11,12,13

Sea World of Texas
10500 Sea World Dr
San Antonio, TX 78251
(210) 523-3000 (voice)
(210) 523-3199 (fax)
1,2,3,5,6,7,9,12,13

Sesame Place
100 Sesame Rd
Box L579
Langhorne, PA 19047
(215) 752-7070 (voice)
(215) 741-5307 (fax)
1,3,5,6,7,12

Six Flags Great Adventure
Rte 537
Jackson, NJ 08527
(908) 928-2000 (voice)
(908) 928-2775 (fax)
1,2,3,5,6,7,12,13

KEY TO SERVICES
1 Accessible restrooms
2 Accessible telephones/TTYs
3 Accessible restaurants
4 Accessible hotels/motels
5 Accessible rides/attractions
6 Accessible parking
7 Wheelchair rentals
8 Sign language interpreters
9 Braille information guides
10 Wheelchair repair services
11 Personal care services
12 Guide dogs permitted
13 Guidebooks for visitors with disabilities

Six Flags Great America
PO Box 1776
Gurnee, IL 60031
(708) 249-1776 (voice)
(708) 249-2390 (fax)
1,2,3,5,6,7,12,13

Six Flags Magic Mountain
PO Box 5500
Valencia, CA 91385
(805) 255-4100 (voice)
(805) 255-4815 (fax)
1,2,3,5,6,7,12,13

Six Flags Over Georgia
PO Box 43187
Atlanta, GA 30378
(404) 948-9290 (voice)
(404) 948-4378 (fax)
1,2,3,5,6,7,12

Six Flags Over Mid-America
PO Box 60
Eureka, MO 63025
(314) 938-5300 (voice)
(314) 938-4805 (TTY)
(314) 587-3617 (fax)
1,2,3,4,5,6,12

Six Flags Over Texas
PO Box 191
Arlington, TX 67010
(817) 640-8900 (voice)
1,2,3,5,6,7,12,13

Universal Studios Florida
Guest Relations
1000 Universal Studios Plaza
Orlando, FL 32819
(407) 363-8000 (voice)
(407) 363-8265 (TTY)
(407) 363-8660 (fax)
1,2,3,5,6,7,8,12,13

Universal Studios Hollywood
100 Universal City Plaza
Universal City, CA 91608
(818) 508-9600 (voice)
(818) 752-8514 (TTY)
1,2,3,4,5,6,7,8,13

Walt Disney World Resort
(Epcot, Disney-MGM Studios and Magic Kingdom)
PO Box 10,000
Lake Buena Vista, FL 32830
(407) 828-1258 (voice)
(407) 345-5984 (TTY)
(407) 934-7081 (fax)
1,2,3,4,5,6,7,8,9,10,12,13

Water Country USA
176 Water Country Pkwy
Williamsburg, VA 23187
(804) 229-9300 (voice)
(804) 253-3399 (fax)
1,2,3,5,6,7,10,12

This directory was compiled by Michele San Filippo, an EXCEPTIONAL PARENT intern.

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Circle #156

Familiar Faces

SUMMER FUN!

Suzanne Ankrom of Rifton, New York says she could have never imagined air travel with an adolescent in a wheelchair—not until last summer, when daughter Christina, 18, who has cerebral palsy and communicates with a Light Talker, was offered the chance to spent a week at an augmentative communication camp in California. Before long, plans for a west-coast family vacation were in the works!

After Christina's week at camp, the Ankroms spent a memorable week seeing the sights in San Francisco, Yosemite and Lake Tahoe. On a day trip to the Muir Woods, a detour from the wheelchair-accessible paved pathways found 18-year-old Christina and dad Mike inside an ancient giant redwood tree. "Now," says Mom, "I wouldn't hesitate to fly off to another distant adventure!"

Alexandra Maniscalco, 4, and father Thomas catch some rays during a seaside vacation in Cape May, New Jersey. Alexandra was born with a translocation of chromosmes seven and nine. She is fed through a g-tube and requires oxygen while sleeping. Parents Thomas and Louise enjoyed visits to Cape May before Alexandra was born, but find it to be the perfect vacation for their daughter as well. "She gets to lay down on the beach and we put her feet in the ocean," says her dad. "It's a different experience for her." When not on vacation, the Maniscalco family resides in Yorktown Heights, New York.

Michelle Coe, 5, of Aurora, Colorado, enjoyed meeting Robin Hood and Maid Marian during a 1993 trip to Disney World. Michelle was born with a defect of the first cervical vertebra which resulted in quadriplegia; she has been ventilator-dependent since the age of five months. Her mom, Ellen, says she has always been determined to give Michelle the same opportunities and experiences as other children of the same age.

A few near-catastrophes occurred during their Florida trip. In a sudden, drenching downpour in the Magic Kingdom, Michelle's power wheelchair and ventilator both stopped working. Difficulties in obtaining a rental ventilator made Ellen vow to bring two along on every future trip—"As with anything we do in life, we come away with new experiences and better ways to plan for the next time. Most importantly, however, all Michelle talks about are the good times and good memories from this vacation. And isn't that what it's all about, anyway?"

Five-year-old Adam Dreisbach waits for a wave with dad Tim during a 1991 family vacation in Myrtle Beach, South Carolina. Adam's mom, Suzan, believes she has found the key to a successful family vacation with a child who has a disability—"You shouldn't stop doing things as a family. You just need to find out what the child likes to do and plan around that. We know Adam doesn't like amusement park rides, but he enjoys any activity involving water; that helps us make our vacation plans, and we have a great time!" The Dreisbachs—Tim, Suzan, Adam, now 8, and Brian, 14—live in Northampton, Pennsylvania. Adam has a seizure disorder.

The Totey family, including eight-year-old twins Allison and Brian, enjoyed visits to several California theme parks during a 1994 family vacation. Mom Janice had high praise for the accessibility of Universal Studios in Hollywood, noting that the tour tram even had a hydraulic lift for boarding heavy power wheelchairs. A high point of the tour came when the twins met Harry, star of the movie *Harry and the Hendersons*. The Toteys live in Renton, Washington—the heart of "bigfoot country"—where Harry and his relatives are local legends.

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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MOVE International

GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

MOVE International is about people who care. About dedicated individuals who took a hard look at their past work and had the courage to call it a failure. About people who are challenged by immobility, and about the people who care about them. People like Linda Bidabe.

ADMITTING FAILURE

MOVE—Mobility Opportunities Via Education—began with children who had severe mental and physical disabilities and attended the Blair Learning Center in Bakersfield, California. In the early 1980s, the staff of the center decided to take a cold, hard look at the outcomes of their efforts with these children.

The results of this evaluation were depressing: Sixty-three percent of the students who had profound disabilities and were nonambulatory were functioning *below* the six-month level of motor skill development. These children had entered the educational system at three years of age. However, by the time they left school at age 22, many seemed to have *fewer* skills than when they had entered. Babies were growing into young adults with painful deformities and bleak futures. Many students had such poor head and trunk control that they could not sit unsupported; most could not feed themselves or use the toilet.

Linda Bidabe, an educator working for the Kern County Superintendent of Schools Office (which operates the Blair Center) realized that one reason for this apparent regression in skills was that the children spent most of their time reclining in bean bag chairs or strapped into wheelchairs. As they grew older and heavier, gravity became the enemy. With increasing size and weight, the children became less able to bear weight on their legs, pull up to a sitting position or take reciprocal steps. With lack of use, their limbs became less flexible and less amenable to manipulation or therapy. Over time, the children's educational program turned into custodial care; teachers and therapists had to spend so much time caring for the children's basic needs—positioning, feeding and toileting—that there was little time left to help the children learn new skills.

PILOT PROGRAM

A dynamic and gifted teacher, Linda refused to accept this situation as the inevitable result of severe disabilities. In the summer of 1986, Linda's office created a mobility pilot program to focus on just three skills—sitting, standing and walking. The students involved in the program were between the ages of six and 16; all had multiple disabilities. None of the children had ever walked. Only one had any speech. The program involved integrating every aspect of the educational curriculum into a physical activity that could help teach specific motor skills. For example, during speech therapy, the children were placed in an upright stander instead of a wheelchair. During art, students would sit in chairs that had been slightly modified to provide support and prevent falls but that would encourage their back and stomach muscles to work throughout the duration of the activity.

The results of the pilot program were astounding. The teachers worked with individual children throughout the day on specific motor skills, such as sitting or standing. Within a matter of days, an individual child would progress from tolerating this activity for a few seconds, to sitting and standing for an hour or more.

Not only were the children mastering the motor skills that had been the original objectives of the program, they were also becoming more alert and interactive—laughing and making attempts to communicate with their teachers and with each other. Giving a child a means of independent mobility—and the opportunity to make choices—became the foundation for the development of additional skills.

Teachers were amazed. Parents were thrilled. It was obvious the program needed to be defined and expanded. Through a Rotary International fellowship, Linda spent a year in Australia replicating the early successes of the program and doing research to write the MOVE curriculum.

EQUIPMENT NEEDS

One of the most pressing problems was the need to design equipment. Linda's early research showed that children

AMBER STEENBOCK

Living a life on the move

For as long as I can remember, I have wanted to get around and go places. This may have something to do with moving being a big part of my childhood.

I was born in Japan. About three months later, my parents and I moved to Colorado. There, my two younger sisters made their appearances.

Even as a very young child, I seldom allowed my physical disability (quadriplegic spastic cerebral palsy) to interfere with my perpetual goal of being on the move. After mastering the art of rolling, I found this to be a relatively fast and efficient mode of travel for my little body.

After kindergarten, we moved to Kentucky. There, I got my first motorized wheelchair. The wheelchair didn't go very fast, but I enjoyed my new freedom, and thought I was hot stuff. So did my new neighborhood friends. Together, we discovered a great new way to have fun. A jump rope was tied to my chair handle, and six or eight roller skaters were given a "high-speed" tow.

A couple of times, I even ran away from home. I packed my little toy suitcase with my favorite things and drove angrily down the sidewalk—but I always changed my mind by the time I turned the first corner.

After eighth grade, we moved to our farm in Oregon and put down some roots. My sisters and I attend Marshfield High School, where I am a senior.

Amber Steenbock enjoys the view from her family's deck with buddies Scooter (on lap) and Rebel.

When my physical therapist introduced me to the MOVE program at the beginning of the last school year, I was interested. She told me that this was no ordinary program. Rather than the therapists telling me what to do, I would be in control of the pace and order in which I progressed. That sounded very cool. So, we went to work.

I wasn't very impressed in the beginning. Learning to balance in a regular chair was hard work. It took a long time and it wasn't much fun. But after I mastered that skill, things started moving faster. Next, I worked on "prompted" standing for three minutes, and then prompted walking, supported from the front or the rear.

In December, I met a brilliant, fun and incredibly understanding woman named Linda Bidabe, the creator of MOVE. Linda brought me a Rifton Gait Trainer. I stood there for a minute, feeling an awesome sense of control. This was going to be the first time I would walk under my own power. I took off across that cafeteria, and I've never looked back.

The Gait Trainer is a walker with adjustable, removable prompts. Already, my "training wheels" have been removed; next I'll lose the seat.

MOVE has opened doors for me. Transfers are easier. I eat lunch in a regular chair. I walk the halls after school and chat with friends. I am able to "dance." Almost every day, I gain confidence, and am surprised by new or better abilities.

–Amber M. Steenbock

Amber M. Steenbock, 17, lives with her sisters Erin, 16, and Audrey, 14, and parents, Mark and Deborah, on a family farm in Coos Bay, Oregon. Amber loves reading, writing and using her computer. She also enjoys working with small children; one of her goals is to become an elementary or pre-school teacher.

with profound disabilities often required more than 2,000 practice sessions to master a single new motor skill. Public education simply did not have the resources to hire the additional personnel needed to hold children in place while they practiced these skills. The equipment that was needed to support the MOVE curriculum did not exist.

In the beginning, Linda and the staff of the Blair Center created their own equipment—using little more than old bicycle parts and imagination. Then, in 1990, Linda asked the Hutterian Brethren, members of a Christian community who operate Rifton Equipment, if they would like to work with the Kern County Superintendent of Schools to meet the unique needs of this program. The equipment had to be versatile enough to serve a variety of students with varying levels of proficiency, yet sturdy enough to be passed down from class to class as children progressed through the program. The equipment needed to support children with the most severe disabilities, yet that support had to be progressively removable as students gained strength and skills.

As a result of this collaboration, Rifton designed and created several key pieces of equipment—the Mobile Prone Stander, the Universal Chair Frame and the Gait Trainer. Each piece of equipment uses a series of "prompts"—belts or straps—that provide support to different parts of the body and can be gradually removed as a child develops skill and confidence.

THE CURRICULUM IN ACTION

MOVE takes a practical, common-sense approach to teaching children to sit, stand and walk.

For years, many doctors, therapists and teachers have believed that in order to walk, children must first learn to push up and crawl. The natural inclination of adults is to begin teaching where children start failing. Unfortunately, this approach did not work well for children with the most severe disabilities. As children worked on skills like crawling or rolling, they grew into adults who were still working on the same skills.

MOVE turned that model on its head. Instead of using a "bottom-up" model based on typical infant development, Linda began by doing a task analysis of the skills the children would need to lead functional, dignified lives—skills like bathing independently, feeding themselves and using the bathroom.

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MARKUS SMITH

Working toward a dream

Markus' physical therapist, Darron Veh, called me in October of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral palsy. We had "tried" many different things to improve his motor abilities, but Markus had made little progress in the last several years. Markus could stand in a prone stander, but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron introduced us to MOVE and the Gait Trainer and Mobile Stander. Markus loved the stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Gait Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his every little success. His self confidence began to grow.

A year ago, Markus told a doctor, "My greatest hope is to walk someday." He was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Gait Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said, "I love having a desk like the other kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

–Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh, P.T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.

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After one year, Simon was able to sit on a standard chair without support and feed himself. Following major surgery to his legs, Simon is now learning to walk.

–P. Norbury

Mrs. P. Norbury, M.C.S.P., S.R.P., is supervising physiotherapist of the Learning Difficulty Services department at Gorse Bank School in Chadderton, England.

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Circle # 41

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Hey, Mister! Is She Retarded?

by Steve Volkert

"Hey, mister! Is she retarded?"
"What?!"
"Is she retarded? She sure acts like she's retarded."

We were on vacation—just a long weekend really. Spending some time at the Iowa Lakes. Just kicking back, relaxing, trying to regroup and recharge. Stacy and I were in the swimming pool, splashing and playing like any other daddy and daughter. We weren't thinking or worrying about the differences our family has learned to live with over the past nine years.

Then along comes this very inquisitive, very straight-forward seven-year-old kid with a question—"Hey, mister! Is she retarded?"

My first reaction was to grab Stacy, get as far away from the pool as possible, and sit down and cry. Then I thought about really letting this kid have it—with both barrels! I could say something like, "How dare you, you blankety-blank little twerp?" Or, maybe if I held her underwater for a few minutes, it would clear her thinking and wash out her mouth!

Dad holds Stacy moments before she had her ears pierced—part of her thirteenth birthday celebration.

Then I looked around. The little girl wasn't alone; she was with three other, slightly older girls who were looking at her in disbelief. One of them even said, "You don't ask questions like that."

I looked into the eyes of the girl who had just ripped my heart out. I didn't see hatred or hurt—only the innocence of youth. From somewhere deep inside me, a voice asked, "So, what are you going to do?"

To make a long story short, we stood in the pool and talked. Talked about what it means to be different. Talked about sign language. Talked about how everybody is special, how all of us have something we have problems with and about working together to help each other. In the end, Stacy had made some new friends. For the next two days, they were inseparable. Then we all went our separate ways.

That was three years ago. Last summer, we were spending another couple of days at the lakes when I heard someone say, "Hey, Stacy! Remember me?"

You guessed it—same kid! Only this time she had different questions—"What grade are you in? What school do you go to? Are you having fun this summer?"

This time, she was talking to Stacy, not about Stacy! Then, this little girl, the same one who had torn my heart out not so long ago, reached out and touched my heart again. It was impossible to hide the tears when I heard her say, "You know what, Stacy? I've been telling all my friends at home about you. And you know what else? I think I'd like to be a special ed. teacher someday!" **EP**

Play ball! The entire Volkert family—(from left) Chad, Steve, Stacy, Mary and Steve—is involved with Challenger League baseball. Parents Steve and Mary coach Stacy's team; brothers Chad and Jeff help individual players during practice and games.

Dad keeps a watchful eye as Stacy, then 4, wades in a river during a family vacation in Minnesota.

Steve Volkert lives and works on a family farm in northwest Iowa. In addition to farming, he works part-time as a parent coordinator for the Parent-Educator Connection Program at the area education agency where his wife, Mary, works as an inclusion associate in a first-grade classroom. Steve and Mary have three children—Chad, 18; Jeff, 15; and Stacy, now 14.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

Help Wanted

Summer and part-time jobs provide valuable experiences.

by Doris M. Willoughby

Did you, as a child or teenager, gain valuable experience through a summer or part-time job? Your son or daughter with a disability can do the same.

I see four stages through which a youngster passes in moving toward adult job responsibility. Although all youngsters move through this progression in one way or another, it may be helpful to analyze this more carefully with a young person who has a disability. The second stage, especially, is often given little thought; but careful attention to experiences at this level can aid greatly in proceeding to the third and fourth levels of responsibility. (See, for example, "Adventures in Babysitting" below.)

1. *Doing chores in the home, gradually taking on more responsibility.* A child may be given responsibility for picking up toys, household cleaning, washing dishes, taking out the trash, caring for pets or helping to care for younger siblings.

2. *Working at a job outside the home while an adult is present for guidance as needed.* Examples may include working as a mother's helper, entertaining children while the parent is present but busy; assisting with jobs at a local business; doing house-cleaning or other chores for a neighbor, under close direction; or learning work skills under the supervision of a teacher or job coach.

3. *Working independently at a job with some responsibility.* The youngster may shovel snow, deliver newspapers, wash dishes in a restaurant, baby-sit for one or two children (with an adult on call in case of serious problems) or do office work.

4. *Holding a job with greater responsibilities.* As a youngster takes on more and more responsibility, he or she can also earn more money. Even at the first level, it is very helpful if children can receive payment for certain jobs; this teaches that successful work brings the agreed-upon wages, while failure results in no wages. I am not suggesting that youngsters be paid for all chores; they also need to learn to carry their own weight as family members. But it is instructive to pay the child a small wage for certain chores—perhaps those that are optional or more difficult.

The volunteer option

While recognizing the importance of earning money, volunteer work can also provide valuable benefits. Sometimes, volunteer work can turn into a paying job with the same organization or group. Even when volunteer work does not lead directly to actual employment, it can offer excellent experience.

Doris Willoughby has worked as a teacher of both blind and sighted children. She is the author of two books on education for children who are blind. She lives with her husband, Curtis, in Arvada, Colorado. Curtis was one of the first blind individuals to be educated and employed as an engineer. Doris is sighted.

This article was adapted from a longer article, "Part-Time and Summer Jobs," which appeared in Future Reflections *(Spring/Summer 1994), the quarterly publication of the National Organization of Parents of Blind Children (NOPBC). NOPBC provides information and support to families of children who are blind or visually impaired. Family membership is $8 per year, and includes a subscription to* Future Reflections. *For more information, contact NOPBC, 1800 Johnson St., Baltimore, MD 21230; (410) 659-9314 (Voice).*

ADVENTURES IN BABYSITTING

A young woman's first job benefits two families

BY BEVERLY K. SHERMAN

After six years of being home with my children, I returned to work in 1991. My son, Benjamin, was six and a half, and my daughter, Anna, was two and a half. Making arrangements for Anna was easy; she began attending a daycare center. But what would I do with Ben? Ben has severe mental retardation. He is non-verbal and nonambulatory, and has a seizure disorder (under control). At the time, he still wore diapers.

Babysitter Dawn Sander, 17, reads a book with Ben Sherman, 10.

Because of his sensory integration problems, the noise and commotion of a daycare center would make Ben miserable. I also knew that the teacher-student ratio would not be adequate. My husband and I also decided against a family daycare home because Ben is very difficult in other people's homes. He is very unhappy unless he is watching his videotapes. He also would not be interested in playing with other children. We needed a sitter in our home.

Ben attends Kirk School, which serves students with mental retardation and multiple disabilities in the suburban Chicago area. My husband, Alan, a com-

puter consultant, arranged his schedule to be home in the morning so he could take Anna to day-care and put Ben on the school bus. For after-school care, we advertised at the local high school, and found a student to come to our home until I returned from work. Over the next year and a half, we used two other high school students. When our last sitter graduated, we found ourselves in a bind.

Alan and Beverly Sherman, with children, Ben, 10, and Anna, 6.

While fretting over where we would find a sitter, I began thinking about what the job really entailed. The sitter needed to get into my house, take Ben off the bus, put him on the toilet, and turn on the television and videotapes. Ben never varies from his routine. It was not a "difficult" job. I just needed a reliable person who could phone my husband or me in case of an emergency.

Stunned, but thrilled

I decided to ask Glady Sander, one of our neighbors, if she thought her daughter, Dawn, might want to babysit for us. Dawn attends the special education program at our local high school. She had always enjoyed coming over and playing with my kids.

Glady was stunned at my request, but phoned four days later to say she and her husband would be thrilled for Dawn to have her first job. However, they were worried that this might be too big a step for her. They were concerned about my son's needs and the responsibility Dawn would be assuming.

They eventually decided to let Dawn work for us, feeling they would never know Dawn's full potential unless she was given the opportunity to try. Glady is home in the afternoons and would be able to stay with Dawn for the first few months while Dawn learned the routine. Glady would also be available whenever a problem came up.

When we asked Dawn what she thought about working for us, she was so excited. She immediately said, "When I go to their house, I can bring in their mail!" We all felt this comment was a good sign because it showed her initiative.

The next Saturday, Dawn and Glady came to our home, armed with a clipboard and a list of questions. I showed Dawn how to unhook Ben's bus harness, how to put him on the toilet and how to work the VCR. We talked about what to do if Ben soils his pants, what to do if he is unhap-

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"Hi, honey, I'm home!"

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But we received a prize more valuable than money. Our daughter was given the opportunity to be gainfully employed. Dawn was to receive much more than a paycheck. The value of this job cannot be calculated in monetary sums.

It has been two years since Dawn began caring for Ben. At the conclusion of her work day, Dawn arrives home with a smile and a spring in her step. As I open the door to welcome our "working girl" home, she often cheerily exclaims, "Hi, honey, I'm home!"

"Pay day" is Dawn's favorite day. She marches proudly into the bank with her paycheck. Some of the bank employees who have gotten to know Dawn have even attended the Special Olympics to cheer Dawn on.

Should you ever have the privilege of meeting Dawn, her job is one of the first things she would tell you about. She is so proud of her caregiver responsibilities and seems to have a real gift for working with children.

As part of a recent English assignment at school, Dawn was asked, "If you could be any person in the world or could have anything you wanted, what would it be?"

Dawn's answer: "To be a teacher and teach kids."

—*Glady Sander*

Glady Sander lives in suburban Chicago with her husband, Dick, and children, Todd, 22, and Dawn, 17.

py and what he likes to eat. We also agreed that Dawn would not answer the doorbell or the telephone.

This first meeting made me realize how complicated this "easy" job really was. I was afraid Dawn felt overwhelmed by the many Jetails we had discussed; still, I felt that with enough time, Dawn would be able to handle the job. It was comforting to know that Glady would be there every day until Dawn understood the routine.

After about a month, Glady felt comfortable merely being in my house while Dawn worked; that is, Glady would be in my living room while Dawn met the bus and took care of Ben in the family room. After a few weeks, Dawn felt ready to do it all by herself. Dawn would call her mom when she arrived at my house, and again after bringing Ben in from the bus. Although Glady would sometimes come by to help Dawn with her homework, Dawn was the one looking after Ben.

The unexpected

The hardest part for Dawn was when something out of the ordinary happened. For example, one time Ben knocked over a picture frame and cut his finger on the glass. Another time a plumber showed up early for an appointment, and repeatedly rang the doorbell. Dawn called her mother and Glady ran over to see who was at the door. These types of situations presented no challenge for

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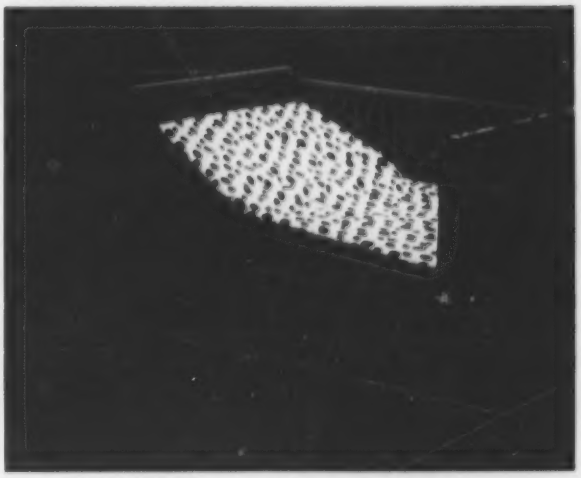

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our other babysitters, but they are learning experiences for Dawn.

Dawn is a terrific babysitter. She truly enjoys being with Ben and he loves her, too. She lets us know each day how Ben did and if anything unusual happened. We increased her responsibility by having her keep track of the times she arrives and leaves our home. Her mom helps her add up the hours each week so we know how much we owe her.

More self-confidence and assurance

We have all seen tremendous changes in Dawn since the job started. She has much more self-confidence and handles Ben with more assurance. She loves telling people that she has a job. Alan and I are proud of her progress and feel good that we gave her this opportunity.

Beverly Sherman lives in suburban Chicago with her husband, Alan, and children, Ben, 10, and Anna, 6.

[redacted]

by Earl Schive

Earl Schive kept his newspaper route for nearly four years.

Last summer, I got a newspaper route. I deliver newspapers every morning by 7 a.m. Every week, I collect money from my customers. I pay my bill at the newspaper office on Fridays, and then I keep the money that is left.

On my first collection day, I felt very nervous. I wondered how I could communicate with my customers. What would they think about me? Would they dislike me or think I am stupid because I am deaf?

I went to the first customer's house and knocked on the door. The woman opened the door and I showed her the money collection cards and pointed to show how much money she owed me. The woman realized I was deaf. She nodded her head and gave me the money with a smile. I still felt nervous but after a few houses, I realized it would not be that hard, so I relaxed.

In November, there was a contest to get new customers. I wondered how I could win one of the prizes. Hearing newspaper carriers could talk to people and ask them if they wanted to subscribe. I couldn't talk so what could I do?

Then I had an idea. My idea was to make a big poster that said, "I deliver the *Boston Globe* in this neighborhood," and explained the full service. I stood near the store where people buy newspapers each Sunday. Every time I noticed people carrying the *Boston Globe* from the store, I approached them and showed them the poster. The first time I tried this, I got two new customers. I did this every Sunday for five weeks. As a result, I got more new customers than any other kid in my town. I won many contest prizes; I got a watch, a $25 gift certificate and cash.

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As I continued delivering newspapers, some customers became my friends. They tried to find ways to communicate with me. For example, Mrs. O'Brien, an elderly woman on my route, started writing notes to me. She left them in her door with her newspaper money. I wrote some notes back to her. Then she started to leave little gifts for me. She treated me almost like a grandson.

Other customers on my route have also become my friends. We find ways to communicate. I have taught some customers some sign language. With others, I write notes or try to understand their lips. We discuss sports and sometimes they ask me questions about myself.

I have learned a lot from having this newspaper route. I have learned to be responsible; I have learned that I can find ways to communicate with and become friends with hearing people; I have learned that I can do as good a job as hearing kids.

Earl Schive, now 20, was born profoundly deaf and has additional mild physical and learning disabilities. He is the adopted son of EXCEPTIONAL PARENT *associate editor Kim Schive.*

Earl wrote this essay when he was 13 years old. It won first prize in the "Deafness" category of the 1988 Creative Contest sponsored by the National Association of the Deaf and WORLD AROUND YOU*, a magazine for deaf and hard of hearing teenagers. (For information about* WORLD AROUND YOU*, contact Gallaudet University, Pre-College Programs, KDES PAS 6, 800 Florida Ave. NE, Washington, DC 20002-3695, 202/651-5340, V/TTY. Subscriptions cost $7 per academic year for five bi-monthly issues; order line: 800/526-9105, V/TTY.)*

WORKING ON THE CONSTRUCTION CREW

by Charles Cheadle

Last summer I worked for Wilhelm Commercial Builders, a construction company in my area.

We spent most of the summer rebuilding a basement in a renovated factory building. The basement floor was above a large underground chamber that had been sealed off years ago. We needed to fill in the lower chamber with concrete to prevent water damage from below. Under the supervision of our foreman, we removed flooring and hauled it in huge pieces to a nearby dumpster. The work was tedious, slow and grueling.

The floor was roughly six inches thick. On the bottom was three and a half inches of spline-jointed Georgia pine covered with one-inch tongue-and-grooved maple. On top of those two layers were two more layers of three-quarter-inch plywood covered with rubber tiling.

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On the job: Charles Cheadle helps other members of his construction crew remove the basement floor of an old factory building.

tions. First, we removed the linoleum-plywood layer in four-foot squares. Next, we removed the maple, which was very securely nailed in place. To take up these two layers, we used wrecking bars which we jammed under the nails to pry them free.

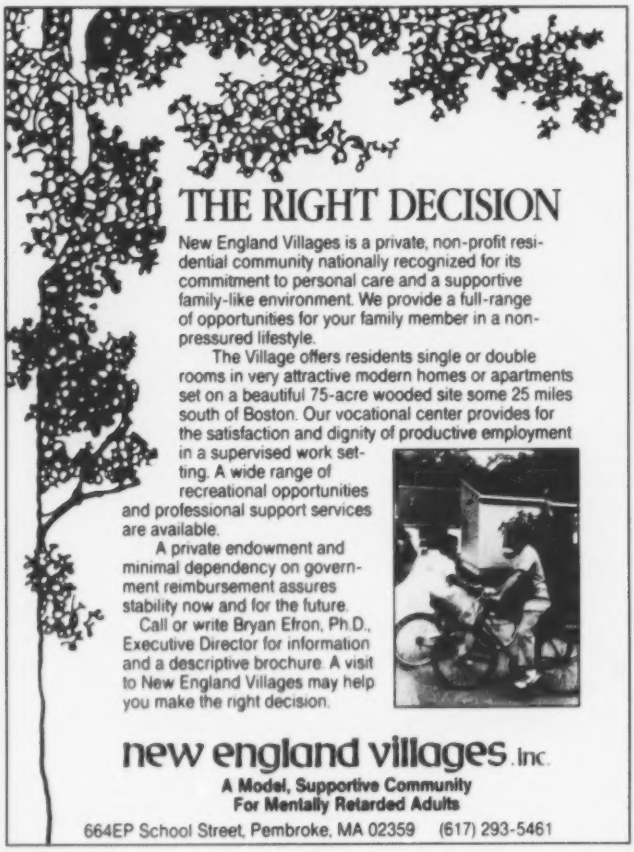
My blindness caused me trouble only when it was time to pick up the wood. I had to be careful not to stab myself. I used a simple technique—"Don't go grabbing wood in a hurry!" I also found that by initially reaching out a few inches above the wood and then carefully picking it up, I could avoid the larger splinters and nails.

Our next step was to remove the pine timbers. When the timbers were cut free we had to carry them out and stack them in the dumpster too. This was the last layer of the floor; when it was removed, our place to stand went with it. Now the surface was full of holes with a seven-foot drop-off. This intimidated me at first, but because the work had to be done, and I liked having a job, I had only one option—I just made sure I was constantly aware of where the holes were and where I was. I figured as long as I wasn't on top of where a hole was, I would be OK. This proved to be a good strategy, and I didn't encounter any hostile or malicious holes subsequently.

The few problems I had did not hinder my productivity in any way. Yes, they did seem difficult at first, but taking an open-minded approach helped me come up with solutions. Careful thought and some planning will go a long way in ensuring a safe and productive work environment. **EP**

Charles Cheadle, 17, has been blind from birth. He lives in Baltimore, Maryland with his adoptive parents, John and Barbara. A junior honors student at Catonsville High School, Charles is a member of the cross-country team and active in Boy Scouts and a local National Federation of the Blind chapter.

Charles' father helped Charles and his older brother get summer jobs with Wilhelm. Though the presence of his older brother was initially reassuring to Charles' supervisors, it was not integral to his success. He has been offered another job with Wilhelm this year—with or without his brother.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Circle #91

Photo: Claire Yaffa

Effective programs for reducing reading failure involve individual or very small group instruction by a well-trained teacher.

Preventing School Failure

Students with learning disabilities have special instructional needs

by Louisa Moats

In the last 20 years, our understanding of many specific learning disabilities has grown significantly. Among the various learning disabilities, disorders of language comprehension, language expression, reading and writing are the most common. Up to 80 percent of the children we categorize as having learning disabilities, in fact, have disorders of language. These language-based disorders include reading and writing disabilities.

Through research we know that listening, speaking, reading and writing are closely related language skills. For example, preschool children with disorders of oral language—meaning listening and speaking—usually develop difficulties learning to read and write. Conversely, most children who encounter reading failure demonstrate a basic deficit in speech perception and speech sound processing.

These children have trouble detecting the speech sounds in words and associating them with letter patterns. For example, younger children with reading disability usually can tell that spoken words like "moats" and "most" are different, but cannot identify which sounds are different or how many sounds there are in each word. They may also have difficulty with rhyming activities, word games (such as pig Latin) and activities requiring them to count or change the sounds in words. They may have unusual trouble learning the differences between words such as "goal" and "gold." I knew one child who sat through an entire lesson on the Gold Rush and thought that the teacher was talking about "goals," like soccer goals.

Children with these language disabilities have difficulty discriminating between words such as "boost" and "boast," or "unanimous" and "anonymous." Such children have a weak sense of word structure which undermines their ability to learn the code of written English. As time goes on, this problem, in turn, undermines their vocabulary, reading comprehension, spelling, written expression and their motivation for language-based learning. Obviously, they are at high risk for school failure.

Do we know how to teach these students? Yes; educational researchers have agreed on the essential components of effective teaching. Model schools and programs with low rates of failure do exist. Do we practice what we know? No; not on a nationwide scale that would make a difference. Clearly, several educational policies and practices must be altered to clear the way for better implementation of good teaching practices for students with learning disabilities.

Early intervention essential

First, reading failure can be prevented for all but a very small percentage of children. Intervention, however, must begin early in kindergarten and first grade. The longer intervention is delayed, the more likely it is that a child's failure will become entrenched. Programs which have been proved effective in reducing reading failure involve individual or very small group instruction by a well-trained teacher. Examples of such programs include Project Read Out of Minnesota, Success for All in Baltimore and Philadelphia, Reading Recovery

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in New Zealand and Ohio, the Winston/Salem Project in North Carolina, Benita Blachman's projects in New York City and Syracuse, and many others.

Effective prevention of reading failure includes reading and writing practice with a wide variety of worthwhile material. But, most importantly, effective prevention includes the direct teaching of speech sound awareness, alphabet knowledge, the links between sounds and symbols and fluent decoding of print (the ability to go from looking at printed words on a page to comprehension of meaning). In the case of reading disability, the nature of the problem suggests the nature of the cure—those children who are not sensitive to words can learn when the word structure is taught to them explicitly. Though not part of the standard reading curriculum, this type of instruction should be available in every school for those who need it.

A full continuum of services

Secondly, the policy known as "full inclusion" should be replaced by the original provision of the Individuals with Disabilities Education Act (IDEA)—a continuum of services and placement options for students with learning disabilities. In the schools I visit, full inclusion has come to mean that students with learning disabilities receive little or no appropriate instruction in mainstream classes. Those who learn differently are not being taught differently.

Typically, teaching assistants are placed in regular classes to adapt curriculum and walk children through inappropriate assignments. Educators often have neither the administrative support nor the time to instruct children in the basic skills they lack using research-supported methods that address their language, attention and memory deficits. Students with learning disabilities may be able to pass courses because the teacher changes their assignments, or someone reads to them, or someone writes for them, but they are *not* learning how to read, write, calculate, solve problems and study.

Mainstream teachers usually have not been trained to teach language in a structured way and do not have the energy, time, commitment or expertise to be all things to all students. Some students with learning disabilities can be mainstreamed with curriculum adaptations, but many need small groups away from the mainstream, many need tutorials and a few need self-contained day programs and residential placements.

It is not *where* instruction takes place, but the *quality and focus* of that instruction that ultimately determine the success of students with learning disabilities. **EP**

This article was adapted from remarks presented by Louisa Moats, Ph.D. at the Summit on Learning Disabilities. Louisa Moats is the director of teacher training and clinical services at the Greenwood Institute in Putney, Vermont. The Summit, sponsored by the National Center for Learning Disabilities, was held in Washington, DC, Sept. 20–21, 1994.

LEARNING DISABILITIES: A NATIONAL RESPONSIBILITY, a report from the Summit, is a summary of recommendations for improving the lives of individuals with learning disabilities. This 24-page booklet costs $4 (including postage). It is available from the National Center for Learning Disabilities (NCLD), 381 Park Ave. South, Ste. 1420, New York, NY 10016; (212) 545-7510 (voice), (212) 545-9665 (fax). NCLD has other available publications, and can provide information and referrals to parents of children with learning disabilities. Contact them for more information.

Participation in Research Studies

Researchers are currently looking for participants to take part in the following research studies. The information has been reprinted with permission from *Orphan Disease Update* (Fall 1994), the newsletter of the National Organization for Rare Disorders (NORD), 100 Rte. 37, PO Box 8923, New Fairfield, CT 06812, (800) 999-6673 (voice), (203) 746-6481 (TTY), (203) 746-6481 (fax).

BRANCHIO-OTO-RENAL SYNDROME

Research aimed at identifying the gene on chromosome 8 that causes Branchio-Oto-Renal syndrome is being conducted by Dr. W.J. Kimberling and Dr. S. Kumar at Boys Town National Research Hospital (BTNRH). Volunteers will be asked for a family history, medical records and a blood sample. Researchers will pay for or reimburse expenses associated with these requests.

• Contact Tom Fowler, BTNRH, BOR Project, 555 N. 30th St., Omaha, NE 68131, (800) 835-1468.

POLYMYOSITIS AND DERMATOMYOSITIS

Researchers are seeking volunteers with polymyositis or dermatomyositis who have blood relatives with any type of myositis. This investigation is looking at genetic factors that might be responsible for certain connective tissue diseases. Volunteers will fill out a questionnaire and donate a blood sample.

• Contact Dr. F.W. Miller or Dr. Lisa G. Rider, Molecular Immunology Lab CBER, FDA, National Institutes of Health, Bldg. 29, Rm. 507, HFM-521, 8800 Rockville Pike, Bethesda, MD 20892, (301) 496-6913.

DIABETES INSIPIDUS

Dr. Robert S. Wildin is studying the genetic causes of congenital nephrogenic diabetes insipidus. He has identified 15 different genetic mutations in the renal vasopressin receptor in different families. He is interested in collecting more blood samples from families he has not yet studied.

• Contact Dr. Robert S. Wildin, Dept. of Pediatric Genetics, UTMB, 301 University Blvd., Galveston, TX 77555-0359, (409) 772-3466.

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IEP Strategies

Getting what your child needs from IEP meetings and annual reviews

by Barbara Ebenstein

How will we educate Risa? I worried about how I would communicate my daughter's special needs to our school district and how the district would respond. How could they possibly understand this beautiful child who loves without words?

Risa entered a special education nursery school class while I was a law student. My professors were understanding of my unorthodox class schedule and sudden absences. Risa experienced one educational crisis after another until I developed an approach to special education that permitted me to obtain the services she required.

I now work as an attorney representing parents in special education matters. I also conduct parent workshops. I never come away from one of these sessions without having learned something useful. The strategies presented here are based not only on my own legal knowledge and experiences, but also on the collected experiences of many parents.

Ten Strategies

1. *Keep "business" records.* Treat your relationship with the school district as a business relationship. All communication should be in writing, and you should keep a copy of every document you submit. Keep brief notes of important telephone conversations. Keep a written record of all verbal agreements, and give a copy to the school district.

Hand-deliver important documents directly, or use certified mail and keep the return receipt.

Keep a diary noting the dates you submit documents. Some regulations require that the district comply with time requirements. For example, they may have 30 days to respond to a written request. If so, you need to know the date you made that request. Legally speaking, if it is not in writing, it never happened.

2. *Document all of your child's unaddressed needs.* A parent's insistence that a child requires a specific service is never sufficient. Every unaddressed need should be described, in writing, by a professional who knows your child or has evaluated him or her for this purpose.

Letters from your child's pediatrician, therapist or other professionals can be brief, but should include a description of the child's special need(s), its educational impact and a "prescription" for needed services.

3. *Review your child's classification.* Many states have lists of conditions that permit eligibility for special education services. These are educational classifications, not medical terms. For example, in New York State a child with a medical diagnosis of attention deficit disorder (ADD) may have an educational classification of "other health impaired" or "learning disabled."

Ideally, special education services should be provided on the basis of a child's individual needs. Unfortunately, some school districts provide children with services according to their classification.

If you are dissatisfied with the services your child receives or his class placement, begin by reviewing his or her classification. Is it the most appropriate classification? Would denied services be available if the child's classification were changed? If so, have your child evaluated by an appropriate expert. Your child's classification may also need to change as he or she develops new strengths and weaknesses.

4. *Cooperate with the school district's reasonable evaluation process.* The school district needs your consent to conduct an evaluation; however, if you refuse, they can request an impartial hearing. The hearing officer will deem the proposed evaluation reasonable, and the district may be permitted to proceed without your consent. All you will have accomplished is the destruction of your relationship with your school district. Save your energy for battles you can win.

5. *Be sure the committee has accurate reports.* If you disagree with an evaluation done by the school district, there are several steps to take. First, review the inaccurate report—what is wrong with it? Was it performed when your child was not taking his usual medication? Were inappropriate tests used? Was the evaluator

Barbara Ebenstein and daughter Risa Handelsman.

Risa Handelsman (third from left) participates in her "communication development" class at the Quaker Ridge Elementary School in Scarsdale, New York.

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Dr. John Handelsman and daughters (from left) Leanne, Risa and Sarah.

unfamiliar with your child's strengths and limitations?

Second, ask about the evaluator's position and credentials. After receiving a devastating speech assessment on my daughter, I discovered it had been written by an inexperienced speech teacher. I obtained a more detailed report from my child's private speech therapist—a woman with a Ph.D. and many years of experience. The district followed the therapist's suggestions and agreed to remove the teacher's report from Risa's file.

If you disagree with the school district's evaluation, you are entitled to an independent evaluation at the district's expense. The district may place a reasonable cap on the cost. If the district disagrees with the necessity for another evaluation, you may need to go through an impartial hearing. But if you know an evaluation is inaccurate, it is worth fighting.

You must state your disagreement with the school district's evaluation before they use it to determine your child's placement. If you disagree later, the district will assume that your objection is to the placement rather than to the accuracy of the evaluation. This becomes a more difficult battle to win.

If all evaluations from experienced professionals are contrary to your expectations, consider whether they might be right. Is it possible that you are denying the severity of your child's problem? If not, pursue other experts at your own cost. If you obtain private reports, it is your choice whether or not to share them with the team. You may decide to share only those documents that strengthen your position.

6. *Build accountability into the child's IEP.* The school district has a legal obligation to make the necessary arrangements to provide related services promised on the IEP. If a related service is not provided as required, parents have a right to full due process. Request an impartial hearing in writing. Most districts will solve the problem immediately rather than face the time and expense of an impartial hearing they will probably lose.

The follow-up of specific educational objectives is more difficult. For example, a child who is included in a regular class may have a classroom teacher, a resource room teacher and a psychologist. Usually, no one is designated to have authority to make sure all of them are pursuing the IEP objectives.

There are several things you can do to prevent this situation. First, be sure the IEP clearly states who will be responsible for follow-up; this can be a brief statement on the front page of the IEP. Second, list only two or three important educational objectives in each IEP category. Limit the objectives to your absolute priorities. Remember, the IEP can specify the teaching method or materials to be used. Finally, make sure all professionals who will be working with the child actually read the IEP and are aware of the objectives they should be working toward.

7. *Work things out before the annual review.* Submit all reports to the committee three weeks before the meeting. Insist that all school district reports be given to you at that time. If there are questions or issues to be resolved, try to work them out before the meeting. The best annual review is a short meeting in which the committee gives approval to what has already been decided.

Many parents believe that they can obtain an impartial hearing to compensate for their own lack of preparation for the annual review. This is a serious error. A due process hearing will determine only whether the school district acted in compliance with federal and state mandates. It is not a second chance for the parents to "get it right" by bringing in late reports.

8. *Negotiate.* The process is not an all-or-nothing deal. Reasonable negotiation is possible. Several years ago, I wanted my child evaluated by an Alliance for Technology Access center far from my home. The school district agreed to pay for the evaluation and purchase suggested computer hardware. I agreed to pay for our transportation and lodging.

9. *Consider all proposals for inclusion carefully.* Federal law requires that children with disabilities be educated in the least restrictive environment. This means including the child in a regular classroom whenever possible. But successful inclusion usually requires support and related services. Sometimes, a school district will include a child without providing needed services. Too often, this is a cost-cutting maneuver which sabotages the child's placement. If you and your school district decide to include your child in a regular classroom, be sure that all teacher training, follow-up procedures, support and related services are provided.

10. *Treat the annual review as your most important business meeting of the year.* Dress for business. Bring a sufficient number of copies of all documents in case they have not been distributed to all committee members prior to the meeting.

Request a meeting time that permits all adult members of a child's immediate family to attend the annual review. If a child's father is involved with the family, he must attend—I cannot stress this point enough. Request a meeting time that permits his involvement. Meetings are often dominated by women. The presence of the child's father lends credence to the family's full participation in the meeting. Special education is not a women's issue; special education is a family issue. **EP**

Barbara J. Ebenstein is a partner in the Law Offices of Harry K. Ebenstein, a family law firm in New York City. She lives with her husband, Dr. John E. Handelsman ("Jack"), and their three daughters, Sarah, 14, Leanne, 11, and Risa, 9.

ASK THE DOCTOR

by David Hirsch, M.D.

Hypotonia; Gastrointestinal Problems

Q Our 14-month-old daughter was recently diagnosed with hypotonia. Her gross motor developmental milestones have been delayed—she did not sit unsupported until one year and she barely stands holding onto furniture now. Her fine motor skills are more age-appropriate, but her language skills are slightly delayed. Our pediatrician has referred us to a neurologist who has done a number of blood and urine tests, an EEG (electroencephalogram or brain wave test) and an MRI (magnetic resonance imaging) of her brain. All these tests have come back "negative." We still do not know the cause of her hypotonia. My daughter's neurologist has indicated that a muscle biopsy may be needed. What do you think?

A Hypotonia or low muscle tone, sometimes called "floppiness in infancy," is not a syndrome or a disease; it is a symptom. There are numerous possible causes of hypotonia in infancy, many of which are very rare. However, most of these causes fall into four categories—disorders of the central nervous system (the brain and spinal cord), disorders of the peripheral nervous system (the nerves that go directly to the muscles), disorders of the neuromuscular junction (where nerves and muscles meet and electrical signals and chemicals are transferred) or disorders of the muscles themselves.

If possible, accurate diagnosis is very important because the diagnosis will influence the treatment, if any. The child's prognosis and any possible genetic implications would also be better understood with an accurate diagnosis.

In your daughter's case, I assume the "negative" tests included the newer types of chromosome testing as well as metabolic testing. Did doctors perform an electromyography (EMG), a test of motor nerve conduction velocities? Is there a family history of hypotonia, or muscle or nerve disease?

A muscle biopsy has become one of the more essential procedures for diagnosing various neuromuscular diseases for which hypotonia is a common symptom. Based on what you have told me, and assuming the other issues we discussed are not helpful in making a diagnosis, a muscle biopsy may be very helpful, especially if your daughter's muscle tone has improved very little during the last six months.

Q My eight-year-old son suffers daily from stomach pain and gastro-esophageal reflux (the symptoms of severe heartburn) for which he has been on various medications (Zantac, Reglan and Propulsid). His esophagus (the muscular tube connecting the back of the throat to the stomach) is chronically inflamed. We have had to seal his permanent teeth to minimize damage from acid reflux and frequent vomiting. He has a small sliding hiatal hernia (the top part of his stomach moves up and down through his diaphragm). Medical tests suggest that his esophageal muscles are weak and uncoordinated.

Our son is very bright but has a learning disability in reading and attention deficit hyperactivity disorder (ADHD) for which he takes Ritalin. These problems frustrate him in school and aggravate his digestive problems. His recurrent vomiting at school embarrasses him. Is there anything else we can try?

A This is an example of a situation where one type of developmental or behavioral problem might be making a separate and unrelated physical problem worse. It sounds like you have tried an aggressive medical approach to your son's chronic vomiting with medications that typically work for similar problems. Zantac decreases stomach acid production. Reglan stimulates motility of the upper gastrointestinal tract, the stomach and the first part of the small bowel. Propulsid (also known as Cisapride) increases the esophageal motility (the ability to push food down the esophagus and keep it in the stomach) and emptying of the stomach. I assume that those medications have been used in the proper combination and dosages. A few other medications, such as Carafate, Urecholine and Prilosec are also available. However, I am not sure if they would be any more effective than those you have already tried.

Your son's pediatrician and gastrointestinal consultant may have to consider other studies to define the most likely cause or causes of his gastrointestinal problems. If it has not already been done, a test called an antroduodenal manometry may be considered. This test assesses the pressures in the lower part of the

continued on opposite page

***In this column,** David Hirsch, M.D., a pediatrician and member of the* EXCEPTIONAL PARENT'S *Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch mentions specific products or medications only to illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, *209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-5748 (Fax).*

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WHAT'S HAPPENING

Publications

• *Expectations* is an annual anthology of children's literature in Braille, for grades three to six. This free publication includes color illustrations with raised edges and a "scratch and sniff" page. Included with each copy is a 1995 calendar printed in both Braille and large print. Contact Braille Institute Sight Center, 741 N. Vermont Ave., Los Angeles, CA 90029, (800) 272-4553.

• *Knowing the Ropes* is a 100-page book for parents of children, ages 4 to 15, with speech and hearing impairments. Topics include parents' feelings and supports, deaf culture and alternatives in communication and education. Free to Minnesota parents; $10 for others. Send payment (payable to the Minnesota Foundation for Better Hearing and Speech) to the Parent Network, MFBHS, 166 4th St. East, Ste. 320, St. Paul, MN 55101; (612) 223-5130 (V/TTY)

• *Prader-Willi Syndrome—A Handbook for Parents* is again available. The book, considered the primary parent-to-parent publication on the syndrome, had been out of print for several years. Order from Prader-Willi Syndrome Association, 2510 S. Brentwood Blvd., Ste. 220, St. Louis, MO 63144, (800) 926-4797 $6 ($7 outside U.S.), includes shipping.

• Learn how to influence lawmakers and policy with the 32-page booklet *Making Your Case.* One free copy per person or organization is available from the Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Bldg., 658 Cedar St., St. Paul, MN 55155; (612) 296-4018, (612) 296-9962 (TTY), (612) 297-7200 (fax). For additional copies, contact Minnesota's Bookstore (612/297-3000, 612/282-5077, TTY).

• *Achieving in Spite of ... A Booklet on Learning Disabilities,* a practical guide for parents and professionals on helping children with learning disabilities succeed academically and socially, is available from the National Neurofibromatosis Foundation (NNFF). Send $1 to cover postage and handling to NNFF, 95 Pine St., 16th Fl., New York, NY 10005; (800) 323-7938 (V/TTY).

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stomach and the first part of the small bowel. Further studies of esophageal motility may also be needed. These tests may be important, especially if more aggressive surgical intervention is being considered. If your son also has had problems with constipation and abdominal distention, doctors need to consider whether he has a condition called "intestinal pseudo-obstruction."

I do not believe that the Ritalin your son takes for ADHD is causing any of his gastrointestinal problems, although this medication can cause abdominal pain and decreased appetite. I also do not think the medications for your son's gastrointestinal condition are affecting the action of the Ritalin significantly. However, any time medication changes are made, your son's doctors and your pharmacist need to consider possible side effects or drug interactions.

It is important to keep your son's teachers informed of his medical condition and the things that seem to aggravate it. Perhaps they can modify his program to decrease the stress he is feeling. Above all, try to be as reassuring as possible to your son. **EP**

Special Olympics World Games

Photo courtesy 1995 Special Olympics World Games.

More than 7,000 athletes are expected to compete in the 1995 Special Olympics World Summer Games July 1–9 in Connecticut at sites in New Haven, West Haven, Hamden, Old Lyme and New London. In addition to the athletes, an estimated 2,000 coaches, 15,000 families and friends, 500,000 spectators and 45,000 volunteers from 140 countries will attend the ninth annual World Games.

Sporting events include aquatics, athletics (track and field), badminton, basketball, bocce, bowling, cycling, equestrian events, football (soccer), golf, gymnastics, powerlifting, rollerskating, sailing, softball, team handball, table tennis, tennis and volleyball.

Opening ceremonies take place Saturday, July 1 from 7 p.m.–11 p.m. The games close July 9.

Participation in Special Olympics events is open to individuals older than five years old who have mental retardation or cognitive delays. Children may begin participating competitively at eight years of age.

An important part of the World Games will be the incorporation of Unified Sports, a program that combines an approximately equal number of athletes with and without mental retardation of similar age and ability on teams that compete against other Unified Sports teams.

Founded by Eunice Kennedy Shriver in 1968, Special Olympics' mission is to provide year-round training and athletic competition in Olympic-type sports by providing participants with "opportunities to develop fitness, demonstrate courage, experience joy and participate in the sharing of gifts, skills and friendship with their families, other athletes and the community."

For more information on this event, contact 1995 Special Olympics World Summer Games, 195 Church St., 16th Fl., New Haven, CT 06510; (203) 498-7773, (203) 498-9618 (fax).

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F. Have you ever bought or recommended a product or service you saw advertised in *Exceptional Parent*? ☐ Yes ☐ No

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Expiration date: July 31, 1995.

EXCEPTIONAL PARENT

April 1995

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Please answer the following questions.

A. Are you a subscriber to *Exceptional Parent*?
☐ Yes ☐ No (If no, please see the subscription card in this issue.)

Name _____

Facility _____

Address _____

_____

City _____ State _____ Zip _____

Phone _____ Fax _____

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ☐ Yes ☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ☐ Yes ☐ No
If Yes, are you a: ☐ Physician ☐ RN ☐ Physical Therapist ☐ Occupational Therapist ☐ Speech Pathologist, Audiologist ☐ Other (please indicate) _____

D. Are you an EDUCATOR? ☐ Yes ☐ No
If Yes, are you a: ☐ Special Ed Teacher ☐ Regular Ed Teacher ☐ Admin/Dir. ☐ Other (please indicate) _____

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ☐ Yes ☐ No
If yes, please explain _____

F. Have you ever bought or recommended a product or service you saw advertised in *Exceptional Parent*? ☐ Yes ☐ No

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357

NEW PRODUCTS

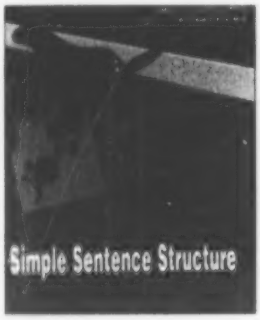
LANDEEZ

This all-terrain wheelchair allows kids to go where conventional wheelchairs cannot. With large tires, plastic rims and a corrosion-resistant frame, this product can handle sand, snow, gravel and grass. The frame assembles and disassembles without tools.

Natural Access, Honolulu, HI 96815

Circle # 195

SIMPLE SENTENCE STRUCTURE



Children with language disabilities often need assistance overcoming word order problems. This language intervention program is designed to help them master sentence forms necessary for communication and comprehension. The program includes speech output, graphics and animation. For Apple IIe, Apple IIGS, IBM and Macintosh computers.

Laureate Learning Systems, Winooski, VT 05404

Circle # 196

ADJUSTABLE POSITIONING TRAY

This height-adjustable Positioning Tray is larger than most in order to accommodate extra-large feeder seats and wheelchairs. The tray adjusts from 17 to 25 inches in height and has an inner width of 24 inches for added wheelchair accessibility. An optional clear tray is also available.

Tumble Forms, Jackson, MI 49204-008

Circle # 197

JUPITER JUMPSUITS

Infants and toddlers who require gastrostomy feeding or heart monitoring now have a unique clothing option: jumpsuits with a front flap that closes with Velcro to give easier access to leads from heart monitors and gastrostomy tubes. These 100-percent cotton-knit suits are machine-washable, available in pastel colors and come with long or short sleeves and pants. Snaps around the legs make changing diapers easier.

Carol Nesper Studio, Cleveland, OH 44106

Circle # 198

AIR LIFT CHILD'S BACKPACK

These backpacks are designed to encourage oxygen dependent children to move around and enjoy play activities. Backpacks available for liquid oxygen units and oxygen cylinder units. They are sized for each child and come complete with padded shoulder straps and adjustable waistbands.

Air Lift Unlimited, Evergreen, CO 80439

Circle # 199

CLASSROOM POSITIONER CHAIR

Although designed for use in the classroom because it adjusts to most desks and tables, this seating system is just as adaptable in home settings. The chair encourages the child to use his or her equilibrium while providing the necessary external support. Features include a contoured seat, seat belt, upholstered back pad and laterals to fit children up to 60 inches tall.

Prospect Designs, New Hartford, CT 06057

Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 products for persons of all ages who have a physical, sensory or cognitive disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers in each listing are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 63) to get more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

BEST COPY AVAILABLE

by Richard Epstein

Cutting Costs in Medicaid and Medicare

Instead of answering a reader's question in this issue, TROUBLESHOOTER columnist Richard Epstein gives his ideas on how to cut costs in the Medicaid and Medicare programs.

Under the U.S. health care system, many people rely on Medicaid and Medicare to meet the cost of their families' medical care. Medicaid is the only health insurance program for thousands of children with severe disabilities. Medicare serves as the primary insurer for many younger and older adults who have disabilities.

Generally, Medicaid covers children until they are 18 years old; Medicare is for people over 65 or for people who have been getting Social Security disability benefits for two years. Because children, even those with disabilities, do not get Social Security disability benefits until they turn 18, a child usually cannot get Medicare coverage until he or she is 20. However, children with chronic renal disease, who need a kidney transplant or dialysis, are eligible for Medicare.

Federal and state legislators are currently discussing ways to cut funding for these programs. The desire to balance the budget and reduce taxes is understandable. However, Medicaid and Medicare are vital programs.

Ways to save

There may be ways to achieve substantial savings in Medicaid and Medicare without cutting essential services. Regulations that govern these programs have become so complex that they may result in unnecessary costs. Changing some rules could result in significant savings.

Managed care

Federal and some state governments seem to have concluded that money could be saved if Medicaid recipients are encouraged to switch from traditional plans to managed care programs such as health maintenance organizations (HMOs). However, Medicaid rules in some states appear to discourage recipients from choosing managed care programs.

When a child with a disability is covered by Medicaid and a parent's traditional group insurance plan, Medicaid generally acts as the secondary insurer. This means Medicaid considers paying any co-pay amounts remaining after the primary insurer has paid its portion of the bill. However, if the parent chooses an HMOs as the child's primary insurer, Medicaid rules in some states appear to prohibit the payment of any co-payments, even when they are significantly lower than they would be if the parent had chosen traditional insurance.

The problem appears to be that HMOs sometimes require co-payments be made *before* services have been performed. Technically, this does not represent an amount remaining *after* the primary insurer's payment.

A great deal of money could be saved if Medicaid paid the co-payments when a child is covered by an HMO and Medicaid.

Medicare changes

Rule changes could also result in significant savings. The rules determine whether Medicare or a group insurance plan is the primary or secondary insurer are so complex that people sometimes are given the wrong information about which is primary.

When that happens, the error must be corrected through a costly process. It may require that claims be refiled with both Medicare and the group insurance program.

According to a Medicare representative, when a person has a disability, is under 65 years of age and is also covered by a group insurance policy that has more than 100 members, Medicare is generally the secondary insurer.

If the group insurance policy has fewer than 100 members, Medicare is the primary insurer, and the group insurer is secondary. However, there are exceptions to these rules. Simplifying the rules would probably be easier and less costly than trying to correct the errors resulting from these complex regulations.

Filing a claim

Other rule changes related to regulations dealing with enforcement provisions, billing, claim determinations and other areas may also result in enormous savings. But perhaps the easiest way to save significant money would be the implementation of a national electronic claim filing and payment system for Medicaid, Medicare and private insurance companies.

The paperwork involved in filing a claim is frustrating, expensive and time-consuming. With computerization, the use of technologically-advanced, electronic "smart cards" could completely eliminate this paperwork.

Inefficient situations

Before the government begins to cut services, the first step should be to eliminate the rules that create inefficient situations. This might reduce expenditures so significantly that there would be no need to cut services.

It is important to write to state and federal legislators to demonstrate the importance of Medicaid and Medicare. You might suggest the approaches discussed in this column as a way to reduce costs. **EP**

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

359

A Special Care Facility Exclusively for Children

At Voorhees Pediatric Facility we provide comprehensive and progressive subacute health care for medically fragile children ages birth to 21 years.

Here's why Voorhees Pediatric Facility is the right choice:

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- Largest pediatric ventilator unit in the country (including pressure vents)
- Strong medical and rehabilitative interdisciplinary team approach
- In-house developmental pediatrician and medical resident program
- Board certified pediatric pulmonologists
- Affiliated with St. Christopher's Hospital for Children and Cooper Hospital's Child Development Center
- Respite care available at our 105-bed facility
- Future programs - Pediatric specialized medical day and home health care
- Caring for children from the Mid-Atlantic states ***since 1982***

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Carl Underland, Administrator
1304 Laurel Oak Road • Voorhees, New Jersey 08043-4592
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Circle #108

SPOTLIGHT ON SUMMER CAMPS

sponsored by Children's Specialized Hospital

CAMP CHATTERBOX

AGES 5-16 AUGUST 20-26
Overnight Camp Program
An intensive therapy camp for non-speaking children & adolecents who use augmentative communications systems and a training program for their parents.

SPORTS & RECREATION CAMP

AGES 7-17 9:30 AM - 4 PM
July 31-August 4, Ocean County, NJ
August 21-25, Union County, NJ
August28-September 1, Union County, NJ
Athletic training & recreation for junior athletes with physical disabilities.

CAMPOREE

AGES 3-6 AUGUST 1-25 9:00 am - 3 pm
Children with attention problems, learning disabilities or speech language deficits.

UNDER THE UMBRELLA

AGES 7-11 AUGUST 1-25 9:00 am - 3 pm
Children with attention problems, learning disabilities or speech language deficits.

FOR MORE INFORMATION CALL 908-233-3720, EXT 352 OR WRITE TO ROBYN SCHAFFER

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150 New Providence Road • Mountainside, NJ 07092

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THE WATER WALKER

* Prone or supine support.
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* Pillow for head support.
* S.M.L

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AQUATIC THERAPY
1903 East B Avenue
Plainwell, MI 49080
(616) 349-9049

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Circle # 118

Finally...Headgear designed just for little kids...

(...And now for Grown-ups too!)

And the healthcare professional's answer to safety.

ProtectaCap® is Plum Enterprises' exclusive, patented ***custom-fitting*** protective headgear designed with the safety, comfort and self-esteem of children in mind. Made with proven Ensolite® foam for superior impact-absorbency, ProtectaCap provides maximum head coverage-- with the comfort and safety of *less than 3 ounces of weight!* Meticulously hand-stitched in a variety of wonderful fabrics, ProtectaCap features our exclusive soft cottonknit Velcroed® chin strap. And ProtectaCaps® are machine-washable and dryable! **Now available in 5 sizes, Newborn thru Adult,** ProtectaCap is ideal for post-surgery, therapeutic activities, neonatal and geriatric care.

"ProtectaCap is wonderful!"
W. Jost Michelsen, MD
Professor/Chairman, Dept. Neurosurgery
Montefiore Medical Center, Bronx, NY

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Order Now
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Worcester, PA 19490
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Fax (610) 584-4151

Medicaid Approved

WORLDWIDE PATENTS PENDING

Circle #12

SCHOOLS, CAMPS & RESIDENCES

National

Bethphage Mission
4980 S. 118th Street
Omaha, NE 68137- 2220
(402) 896-3884
Where potential comes to life! Serving over 1500 children and adults with dev. disabilities in 16 states, Great Britain, Latvia. Residential, vocational, employment, respite, in-home support, spiritual development. Eight decades of caring.

The Guided Tour, Inc.
7900 Old York Rd., Suite #114-B
Elkins Park, PA 19027-2339
(800) 783-5841/
Fax (215) 635-2637
The Guided Tour, Inc., founded in 1972, has enabled thousands of men & women 17 yrs. & over with developmental and physical challenges to achieve greater independence through travel. For info & free materials, call or fax. Irv Segal, DCSW, LSW-Director

California

St. Vincent's
P.O. Box 669
Santa Barbara, CA 93102-0669
(805) 683-6381
Therapeutic home-like residential program for D/D children, 6-21. Teaches basic care, independent living, social & community skills.

Connecticut

CIB/Oak Hill School
120 Holcomb Street
Hartford, CT 06112
(203) 242-2274
Oak Hill School has over 100 year's experience in meeting the needs of children with multiple disabilities and believes that each student, regardless of the severity of his/her disability, can make progress. Our residential education programs are community-based and provide opportunities for stimulation, friendship and peer interaction at school and home.

Florida

Ralph J. Baudhuin Oral School
3375 S.W. 75th Avenue
Ft. Lauderdale, FL 33314
(305) 475-7324
A humanistic learning environment for children, birth–8th grade with communication disorders, learning disabilities and ADD.

Threshold, Inc.
P.O. Box 1110
Goldenrod, FL 32733
(407) 671-7060

Georgia

Agape Village
3711 Agape Village Rd.
Macon, GA 31210
(912) 471-3700
Providing mentally disabled with 50 acre protected place to live, work in greenhouses and enjoy active life with supervision.

Annandale Village
3500 Annandale Lane
Suwanee, GA 30174
(404) 945-8381
Private, nonprofit community for adults with developmental disabilities. Full residential, day, and evening programs and services promote well-balanced lifestyles which include a broad range of activities. Located on 125 wooded acres near Atlanta.
See ad on page 77

Illinois

Allendale School
PO Box 1088
Lake Villa, IL 60046
(708) 356-3334
Allendale School is a special education program providing comprehensive services to youths with emotional/behavioral disabilities.

Kansas

Heartspring
2400 Jardine Drive
Wichita, KS 67219-4699
(316) 262-8271
Heartspring serves students ages five through 21 who have multiple disabilities and communication disorders. We serve residential school and day-only students. Outpatient assessments, short-term treatment programs, and hearing center services are also offered.
See ad on page 6, Circle #6

Kentucky

The Stewart Home School
Box 20
Frankfort KY 40601
(502) 875-4664
Progressive education, home environment for mentally handicapped children and adults. Multiple recreation and activities. Year round program. Est. 1893. Call or write for brochure.
See ad on page 66

Maryland

The Harbour School
1277 Green Holly Drive
Annapolis, MD 21401
(410) 974-4248
Serves LD & multi-handicapped children ages 5 through 21. Services include counseling, OT, job training & a HS diploma.

Massachusetts

Cotting School
453 Concord Avenue
Lexington, MA 02173
(617) 862-7323
Cotting School welcomes boys & girls ages 3-22 with physical, medical, learning & communication disabilities. We offer individualized academic, pre-vocational and social experiences to build confidence & enhance students' self esteem.
See ad on page 57

The Ivy Street School
200 Ivy Street
Brookline, MA 02146
(617) 738-7982

Latham School; R.R.C.I.
P.O. Box 1879
1646 Main Street
Brewster, MA 02631
(508) 896-5755
Special education / residential facility for girls ages 8-22 with mild dev. delays and ED/ BD
Contact: Shirley Landers-Pfautz

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 01236
(413) 528-2523
For children and adults who have severe neurodevelopmental disabilities and complex medical problems. Private, non-profit residential setting in the Berkshires,offering a comprehensive approach to each individual's well-being with integrated educational, medical and rehabilitative services.
See ad on page 28

League School of Boston
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260

The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000
Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities. 12 mo. day/residential.
See ad on page 77

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Day/residential school for children with develop. disabilities, behavior disorders age 3–22. Integrated preschool, inclusion services. staff intensive program., functional activity based curriculum., supported employment in modern school and group homes.
See ad on page 22

New England Villages, Inc.
664 School Street
Pembroke, MA 02359
(617) 293-5461
Exceptional private community for MR adults offering a range of residential options, vocational, recreation and social opportunities.
See ad on page 59

St Coletta's of Massachusetts Cardinal Cushing School and Training Center
400 Washington Street
Hanover, MA 02339
(617) 826-6371
See ad on page 81

New Jersey

Githens Center
40 Cedar Street
Mount Holly, NJ 08060
(609) 261-1667
Providing a school; DT, PT, ST, day care; respite; medical services; adult activities and family support for individuals with physical and other disabilities.

LARC School
Creek Rd. & Park Dr.
Bellmawr, NJ 08031
(609) 933-3725
Serving developmentally delayed multiply handicapped students 5 to 21 with educational, therapeutic and recreational services.

Matheny School and Hospital
Main Street
Peapack, NJ 07977
(908) 234-0011

361

A residential and day facility for young people with severe physical disabilities (ages 3-21) Also adult services and respite care.

New Hampshire

Crotched Mountain Rehabilitation Center, Inc.
1 Verney Drive
Greenfield, NH 03047
(603) 547-3311, ext. 235
A comprehensive preparatory school and rehabilitation center providing the best in education, a guided return to the community, access to community housing, education, and support services for lifelong planning.
See ad on page 13

New York

Pathfinder Village
for Down Syndrome
Edmeston, NY 13335
(607) 965-8377

Conductive Education Center of Long Island
91 N. Bayview Ave.
Long Beach, NY 11520
(516) 377-0591

Ohio

Camp Nuhop
404 Hillcrest Drive
Ashland, OH 44805
(419) 289-2227
Summer residential camp which serves LD/BD-ADD children. Eleven programs are offered according to age and ability. Founded in 1974.

Pennsylvania

Camphill Special School
1784 Fairview Rd.,
Glenmoore, PA 19343
610/469-9236;
FAX 610/469-9758
Children's Village, DD, residential/day programs, extensive therapies. Waldorf-based curriculum,focus on arts/festivals. School year/summer camp, pool, equestrian therapy. Students share homes with curative educators & staff children. On-campus medical staff & Facility. IMAGINE THE BEST!

H.M.S. School for Children with CP
4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566
See ad on page 78

Keystone City Residence
406 N. Washington Ave.
Scranton, PA 18503
(717) 346-7561/(800) 747-4988
Keystone Camp in Pocono Mtns. for persons with developmental disabilities. 31st year. Specializing in recreation, cultural & performing arts, sports services for Prader Willi Clients. Well trained exp'd. staff. ACA accredited, sessions from 2 weeks.
See ad on page 78

Lee Mar Summer Camp & School
360 E. 72nd St. Ste. A-711
NY, NY 10021
(800) 8LEEMAR/
Fax (215) 635-2637
43rd year of camp leadership in beautiful Pocono Mtns. Co-ed 5-21yrs. Balanced program geared toindividual needs of campers. Aca-demics, speech & language, socialmotor & perceptual training & innovative recreational & athletic activities.
Contact Ms. Lee Morrone.
See ad on page 77

Martha Lloyd Community Services
190 West Main Street
Troy, PA 16947
(717) 297-2185
Superior quality community living opportunities for men and women with mental retardation. life skills; vocational programs; job opportunities; easy access to community resources; experienced, caring staff; excellent health care; annual fees among nation's lowest.
See ad on page 56

Melmark
Wayland Road
Berwyn, PA 19312
(610) 353-1726
A unique community of alternatives near Valley Forge, Pa. Children/adolescents/ adults receive special ed/adult day programs/ OT/ PT/ speech-language/aquatic/pet/ music therapy/horsemanship. Self-help/ safety skills and community involvement promote a more independent life style.
See ad on page 44

The Devereux Foundation
(800) 345-1292, Ext. 3045
(610) 964-3045 fax
(610) 971-4600
Residential, day and community-based treatment centers nationwide. Comprehensive services to individuals of all ages who have emotional disturbances, developmental disabilities, mental retardation, dual diagnosis, autism, and post-head trauma.
See ad on page 21

The Pathway School
162 Egypt Road
Norristown, PA 19403
(610) 277-0660/
Fax (610) 539-1973
Exceptional Children 5-21
Structured program: LD; NI; ADD; TBI; PDD; mild to moderate social and behavioral disorders.

Woods Services
RT. 213, Langhorne, PA
(215) 750-4231
Woods services, founded as the Woods School in 1913 provides specialized residential, educational and therapeutic services to children, adolescents and adults with developmental disabilities, emotional disorders, physical and sensoral handicaps and challenging behaviors.

South Dakota

Children's Care Hospital & School
2501 West 26th Street
Sioux Falls, SD 57105-2498
(605) 336-1840/800-584-9294
Private, nonprofit facility with outreach, outpatient, day school, and residential services for children with disabilities. Multi-disciplinary teams provide individualized,family-centered services. Pediatric rehabilitation program now offered.

Tennessee

The King's Daughters' School
Columbia, Tennessee 38401
Ages Seven-Adult
(615) 388-3810

Tall Pine Camp
114 Tall Pine Circle
Tellico Plains, TN 37385
(615) 261-2329/(615) 261-2138
A special place for special needs campers. A co-ed, 6-week residential camp for learning disabled & mild MR. Prof. staff & nurse, 2, 3, 6 -week sessions. Traditional camp activities, equestrian and computer programs. 26th year in Smoky Mtns-SE Tenn. FREE BROCHURE

Texas

Willow River Farms
PO Box 450,
San Felipe, TX 77473
(713) 525-8482
Organic farming & artisan community meeting the special needs of adult men & women with mental retardation. Beautiful rural atmosphere.
See ad on page 59

West Virginia

CONCORD - Residential & Training Center and School
P.O. Box 39
Yellow Spring, WV 26865
(800) 344-6817:
Fax (304) 856-3768
Comprehensive service for youths and adults with mental retardation and dual diagnoses-noncompliance aggression, pedophilia, fire-setting, etc. Group home living on campus and in community. Strong Behavior management.

Wisconsin

Chileda Habilitation Institute
1020 Mississippi Street
La Crosse, WI 54601
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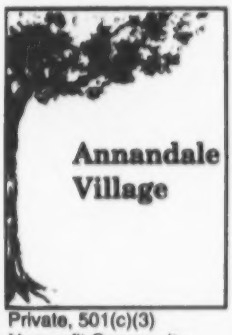

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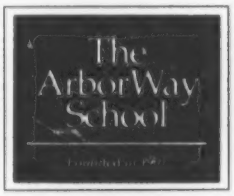

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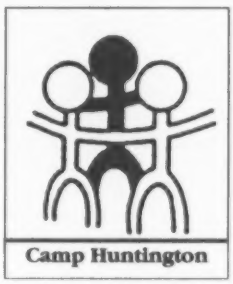

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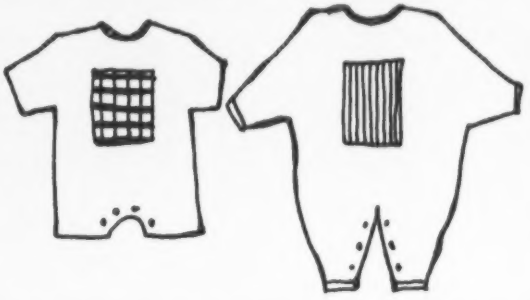

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Circle #214

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Information from The National Parent Network on Disabilities

The National Parent Network on Disabilities Board of Directors

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Executive Director

Change on Capitol Hill

Sen. Frist Named Chair of Disability Policy Subcommittee

Sen. Bill Frist, R-Tenn, is the new chairman of the Disability Policy Subcommittee of the Senate Labor and Human Resources Committee. The freshman senator, a 1974 graduate of Princeton University and 1978 graduate of Harvard Medical School, is a Nashville surgeon specializing in heart and lung transplantation.

At the Vanderbilt University Medical Center's Vanderbilt Transplant Center, which he established in 1986, Frist pioneered innovative diagnostic techniques and performed the first pediatric heart transplant and first lung transplant in Tennessee. The author of more than 100 articles and abstracts on medical research and policy, Frist has also published *Transplant*, a 1989 book examining the social and ethical issues of transplantation.

Frist received the Distinguished Service Award from the Tennessee Medical Association in 1992 for his efforts in successfully organizing a grassroots campaign to return the organ donation card to the Tennessee driver's license. That same year, he was asked by then Gov. Ned McWherter to serve as chairman of the Tennessee Task Force on Medicaid.

Sen. Tom Harkin, D-IA, the subcommittee's former chairman, remains a subcommittee member.

Morrissey Named Staff Director of Disability Policy Subcommittee

Patricia A. Morrissey, Ph.D. has been hired as the staff director of the Senate's Disability Policy Subcommittee, chaired by Sen. Bill Frist, R-Tenn. A graduate of Hartford Community College, Stetson University and Pennsylvania State University, Morrissey is a long-time disability-rights advocate and government worker, having held positions at the House Committee on Education and Labor, Rehabilitation Services Administration in the Office of Special Education and Rehabilitative Services and General Accounting Office.

Most recently, Morrissey was vice president of Government Relations for Community Programs and governmental relations specialist at the law firm of McGuiness & Williams. From 1991 to 1994, Morrissey was vice president of Employment Advisory Services, Inc., where she advised corporate, public and federal clients on federal disability policy. She also served as a technical advisor to and appeared in commercial training videos on the Americans with Disabilities Act (ADA).

Morrissey is the author of several books on disability-related topics, including the *Employment Policy Foundation's Disability Etiquette in the Workplace*, the Vocational Education Association's *Educator's Guide to the Americans with Disabilities Act* and *LRP Publications' A Primer for Corporate America on Civil Rights for the Disabled* and *Employer's Guide to the Americans with Disabilities Act.*

Sen. Bill Frist, R-Tenn, the new chairman of the Disability Policy Subcommittee.

Rep. Cunningham Heads Subcommittee on Early Childhood, Youth and Families

Rep. Randy "Duke" Cunningham, R-CA, has been named chairman of the House's Early Childhood, Youth and Families Subcommittee. This subcommittee has jurisdiction over the reauthorization of the Individuals with Disabilities Education Act (IDEA). The subcommittee's ranking minority member is Rep. Dale Kildee, D-MI. Hans Meeder will serve as the key staff member to this subcommittee as well as to the full Economic Opportunity Committee, previously known as the Education and Labor Committee, chaired by Rep. William F. Goodling, R-PA. The ranking minority member on the full committee is Rep. William Clay, D-MO.

Legislative Update

Senate Sets IDEA Reauthorization Calendar

Patricia A. Morrissey, staff director of the Senate's Disability Policy Subcommittee, has issued a tentative schedule of events for the reauthorization of the Individuals with Disabilities Education Act (IDEA):

- Immediately: One-year extension of IDEA, Parts C through H.
- May 1995: Two days of informational hearings on the education of students with disabilities.
- June 1995: Four days of briefings for subcommittee staffers.
- Fall 1995: Reauthorization bill drafted, two

continued on page 80

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Gail Johnson with sons Eric Jr., 13, and Isaiah, 9. Johnson and her husband, Eric, also have a daughter, Ain, 19.

New Staff Announcement

NPND is pleased to announce that Gail D. Johnson joined the staff in January as development and program specialist. Her chief responsibilities are the Toys "R" Us Project which includes the third edition of the *Toy Guide For Differently-Abled Kids* due to be released this spring, development of special projects and providing members with parent-to-parent support and information, including information on legislative activity directly related to families of children with special needs.

Johnson, a mother of children with special needs, was formerly the Coordinator of the Association for the Care of Children's Health (ACCH) Parent Network, a national network of approximately 2,000 parents and family members of children with special needs.

For the past seven years, Johnson has been a speaker and consultant for many state and national programs on topics including family and professional collaboration, parent-to-parent support and networking, cultural competency and parenting children with special needs. She frequently presents workshops and conference talks to parents and professionals about family-centered, community-based and culturally-competent service delivery.

continued from page 79

days of reauthorization hearings and mark-up of the bill.

• November 1995: Senate floor debate on bill.

The House may have a similar schedule and may hold joint hearings with the Senate in the spring.

In conjunction with the Consortium for Citizens with Disabilities, the National Parent Network on Disabilities (NPND) has agreed to lead the identification of issues and the development of a panel to describe how schools can be most responsive to families. This work is anticipated to shape the reauthorization hearings in the spring and summer.

OSERS Releases "Vision" Paper

In February, the Office of Special Education and Rehabilitative Services (OSERS) released a draft of its "vision" paper outlining its proposal for the reauthorization of IDEA. This draft of the paper is intended for review by interested groups and organizations. NPND has had extensive conversations with Judy Heumann, assistant secretary of OSERS, and Tom Hehir, director of the Office of Special Education Programs (OSEP), concerning the preliminary drafts of the paper, which will eventually become the Clinton administration's recommendations for IDEA reauthorization.

As *Exceptional Parent* went to press, an updated draft of the proposal was slated to be issued in late March.

Copies of the proposal are free. Contact OSEP, 600 Independence Ave., SW, MES Building, Rm 3086, Washington, DC 20202-2570, (202) 205-5507 (voice), (202) 205-9754 (TTY), (202) 260-0416 (fax), or request a copy through the Internet at thomas_hehir@ed.gov.

Unfunded Mandates

The House and Senate has passed unfunded mandate legislation, which limits Congress from imposing mandates on states without authorizing federal funds to help with their implementation. Through the efforts of the Family Action Network (FAN) to Save IDEA, NPND's special project in which FAN members contact legislators on key issues, we have received letters from Rep. William F. Goodling, R-PA, Sen. Dick Kempthorne, R-ID, and the Congressional Research Service stating that IDEA and the Americans with Disabilities Act (ADA) will not be dismantled because they are not considered unfunded mandates. These assurances will be of great importance as the reauthorization of IDEA proceeds.

Corrections Day

The National Governors' Association (NGA) has written to House Speaker Newt Gingrich requesting that IDEA be modified, even before reauthorization, during "Corrections Day," a yet-to-be-announced day proposed by Gingrich for the House to "fix" the technical aspects of any law "in need of fixing." NGA has asked the House to review several issues related to IDEA, particularly at ways to give states more flexibility in the spending of IDEA funds.

NPND opposes any attempts to amend IDEA before the reauthorization process takes place. NPND has alerted members about this through its Fax Tree program and in a FAN alert. For more information, contact NPND, 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

A Parent's Perspective on *Bright Futures*

Bright Futures: Guidelines for Health Supervision on Infants, Children, and Adolescents, a guide supported by the federally-funded National Center for Education in Maternal and Child Health, not only talks about the integration of health services with child development, human services and education, but it actualizes a family-centered, culturally sensitive, community-based approach to provide care to children and their families. This comprehensive guide equips health care professionals with techniques that put families in the "center ring," enabling families to be meaningful participants in the care of their children. Cost is $22.35 (includes shipping and handling); bulk discounts are available. Order from National Maternal and Child Health Clearinghouse, 8201 Greensboro Dr., Ste. 600, McLean, VA 22102, (703) 821-8955, ext. 254 or 265, (703) 821-2098 (fax).

For more information about *Bright Futures* other than ordering, contact National Center for Education in Maternal and Child Health, 2000 15th St. N, Ste. 701, Arlington, VA 22201-2617, (703) 524-7802, (703) 524-9335 (fax).

—Gail D. Johnson

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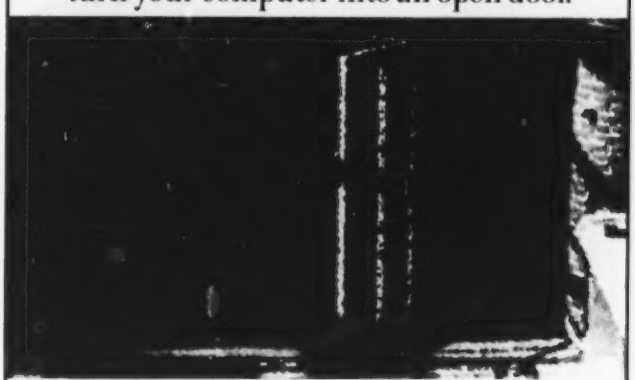

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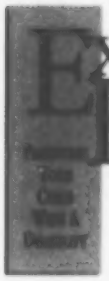

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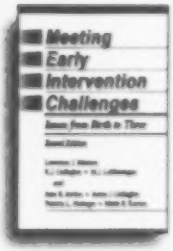

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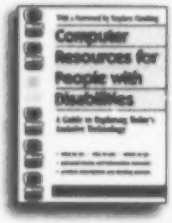

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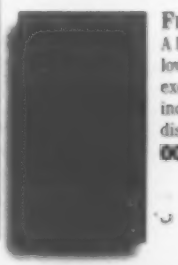

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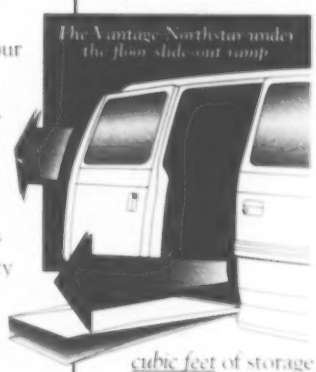

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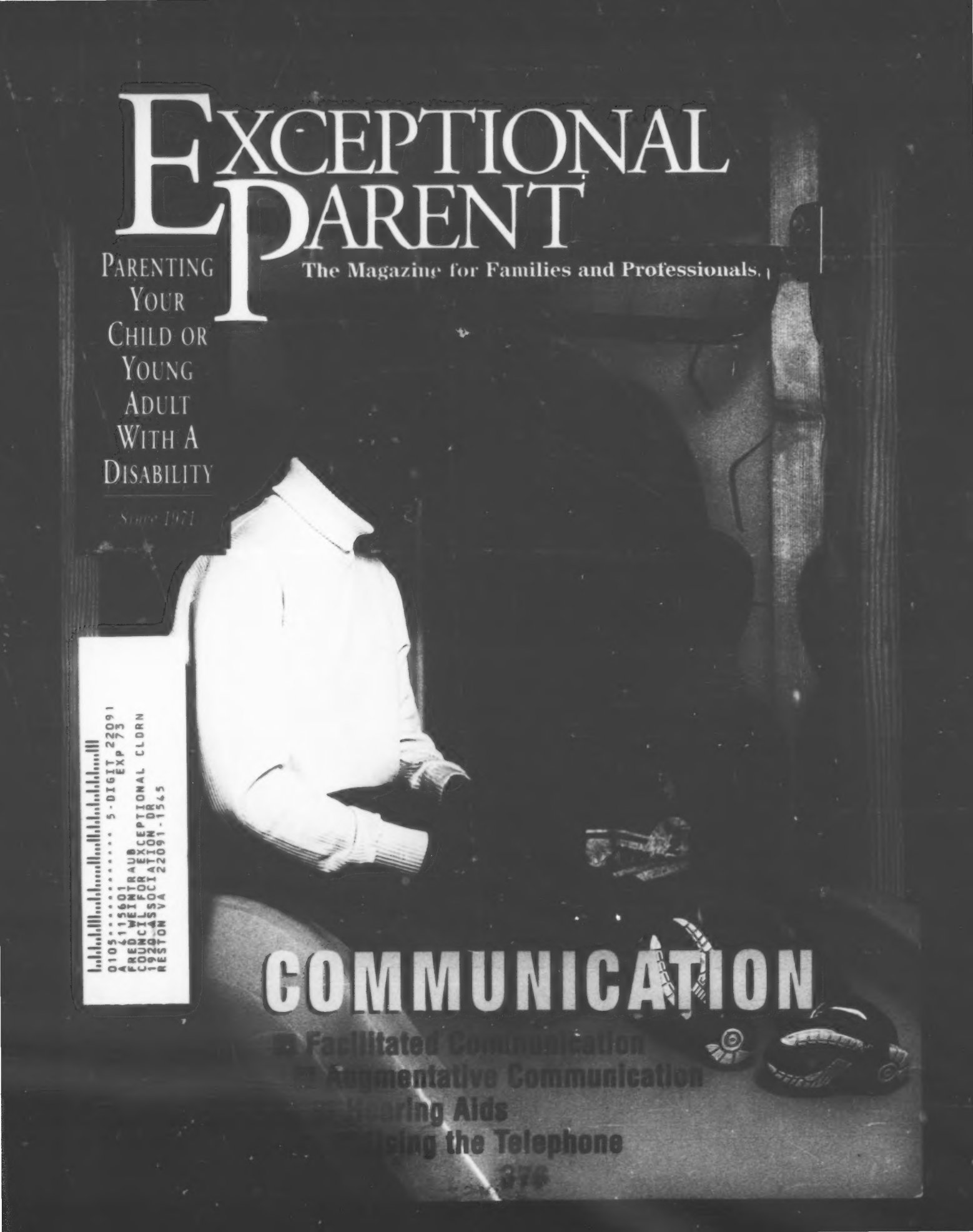

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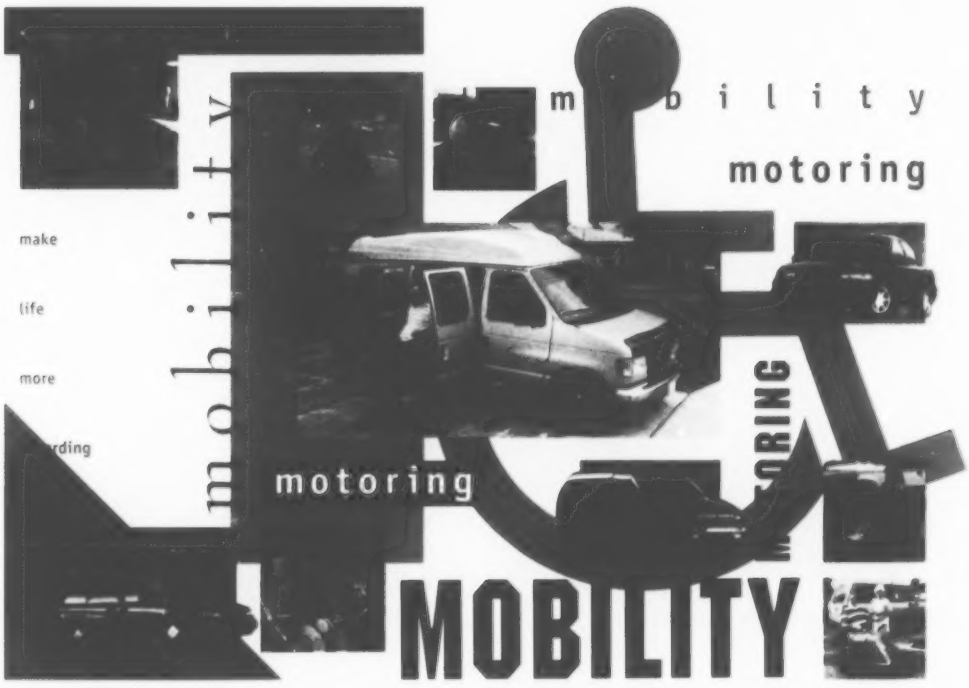

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MAY 1995 VOL. 25, ISSUE 5

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Cover: *Benjamin Wainwright, 5, practices signing with mother Tammy. According to his mom, Benjamin has worked hard to learn to communicate with younger brother Byron, 2, who has mental retardation and uses sign language. Benjamin helps Byron practice the signs he learns during therapy sessions at the Kennedy Krieger Institute in Baltimore, Maryland, and makes sure sister Janicka, 4, and dad Benjamin are learning the signs as well. Byron's speech-language pathologist, Judi Rosenstein, was one of several Kennedy Krieger staff members contributing to this special issue on communication.*

Benjamin lives with his family in Edgewater, Maryland. He attends Hillcrest Elementary School and enjoys playing outside on his swingset. Photo: Robert Smith Jr.

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EDITOR'S DESK

Controversial topics

This issue of *Exceptional Parent* deals with several topics that arouse much controversy and emotion on the part of parents and professionals. As part of our look at communication, we present several perspectives on facilitated communication (FC). And, in his regular department, *Ask the Doctor,* David Hirsch, M.D., discusses the controversial topic of "smart drugs."

STANLEY D. KLEIN, PH.D.

Both topics have received a great deal of media attention, and as I meet with parents and professionals in my travels, I am often asked about them. Such questions typically come from dedicated, caring parents who are troubled and angry about the opposition of many professionals to FC, "smart drugs" or other relatively new approaches. Each time I speak with one of these parents, I remember the movie *Lorenzo's Oil,* the true story of courageous parents who struggled to find answers for their son without the support of the health care establishment. But at the same time, I look back some 40 years and remember my first experience with one of these "breakthroughs." In that instance, a consulting psychologist demonstrated that a youngster with severe physical disabilities and no understandable speech was *not* consistently responding "yes" or "no" to the questions I—and others—thought he was answering. It was shocking and demoralizing to realize we had wished so hard for the youngster's success that we had tricked ourselves into believing it was so.

Several years later, as a beginning clinical psychologist, it was my sad task to demonstrate that a different child could not actually read the word "mother" as her parents and teacher believed. Instead, she said "mother" any time she saw the letter "M"—upside-down, sideways, and with any other scribbles nearby—just as she did when she saw the letters "m-o-t-h-e-r."

Some truths are clear and will never change—parenting is hard work and parents will do whatever they can on behalf of their children. All of us—parents and professionals—are human, make mistakes and are inconsistent, because life is like that. We work each day on behalf of children and young adults with disabilities with as much hope and strength and wisdom as we can muster—and, yes, we wish for miracles.

Over the years, I have listened with wishful interest and respect to reports of "miracles"—diets, for example, that claimed to dramatically alter mental retardation or mental illnesses. Each time, although it seemed a few individuals appeared to benefit from these treatments, most did not. And the proponents of these "miracles" were unable to explain their failures—except, sometimes, to blame parents for not carrying out instructions properly. Despite these experiences, when I first witnessed FC and heard reports of this communication breakthrough, I hoped—somehow—it was true.

The reading and research we did in preparing this issue has convinced us that FC is not a valid approach to communication. Nonetheless, we have included reports from readers who believe FC has been helpful for their children. Similarly, I have invited Syracuse University professor Douglas Bikden, who introduced FC to the United States and remains a proponent, to comment in a future issue. Some readers may find this inconsistent, even confusing. But this magazine remains open to parents and professionals with differing opinions. I have known Doug Bikden for many years and respect his dedication and caring; we also respect the observations of parents who believe FC works for their children. Our mission is to inform our readers as completely as possible. We trust that the information we provide gives both parents and professionals the power to act responsibly and with compassion.

—*S.D.K.*

As the academic year draws to a close, we say farewell and extend thanks and best wishes to three fine journalism interns from Boston University—Andrea Kamens, Jennifer Koerber and Michele San Filippo—who have helped us in many ways for many months. Congratulations on your graduation. We also welcome two new editorial staff members, Siobhan Mullins and Naomi Chedd.

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LETTERS

"All Together, Now!"

Many articles have made me want to sit down and write you, but after reading "All Together Now," the guest editorial by Justin Dart (February 1995), I finally did. This piece should be a warning cry to your readers that we must not become complacent with respect to hard-won gains made on behalf of people with disabilities.

I worked for two congressmen in the 1970s, and have always followed the political scene closely. I believe that politics is the art of compromise, but today's political climate seems to lack the kind of give-and-take that is necessary to move ahead. It is disturbing to think that the majority party in Congress could seek to undermine the basic rights of our loved ones.

K.C., Maryland

■ I could not agree more wholeheartedly with Mr. Dart. It is of crucial importantance that we all voice our opposition to any congressional actions designed to weaken the American with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA) or any other statutes protecting children and adults with disabilities.

Today's legislators should understand that Congress passed IDEA—the law ensuring that children with disabilities receive a public education—as a cost-saving, not a cost-incurring, statute. The entire purpose of IDEA was to enable our children to develop into economically productive citizens of our society. Let us work together for victory in this watershed legislative session of the United States Congress.

J.P.G., Tennessee

Child Care

I am the inclusion/special needs representative for the Arrowhead Association for the Education of Young Children, an affiliate of the National Association for the Education of Young Children. I have assisted in daycare centers and preschools and was a preschool teacher for a short time. I am also an experienced respite care provider.

The entire February issue really got me excited. I immediately started to write to some of the organizations listed in the resource directory so I could make contacts for information.

I love your magazine!

J.E., California

■ I want to commend you on the wonderful job you did with the articles on early childhood (February 1995). The magazine provided a lot of really useful information, and the stories from real families about their child care experiences were superb.

I want to correct several statements in "Child Care and the ADA." First, with regard to the "direct threat" exception—in the ADA regulations on "public accommodations"—a child may be excluded only if he or she poses a threat (defined as "a substantial risk of harm") to others; a child *cannot* be excluded because of risk to self. This confusion has arisen because the ADA regulations dealing with *employment* allow the exclusion of individuals who pose a risk to themselves.

It is also a bit misleading to say that

continued on page 6

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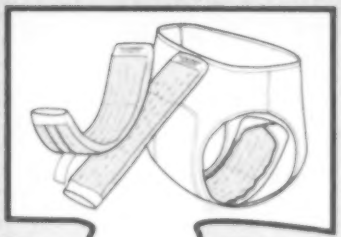

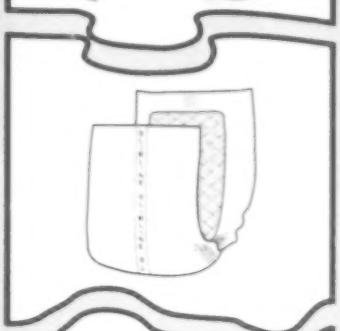

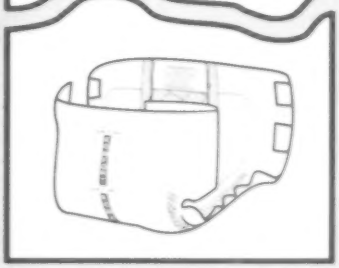

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to exclude a child for this reason, a child care provider "must document efforts made to include the child." Any decision about excluding a child must be made using objective information—such as medical information—not sheer speculation. If the threat of harm can be eliminated through reasonable accommodations in the program, this must be done. In any case, the "direct threat exception" is a very narrow one, and will not ordinarily be considered a proper basis for a child care program to exclude a child.

As you mentioned in the article, the Child Care Law Center provides a number of publications on this topic. I wanted to add that all publications are also available in Spanish.

Abby Cohen, Managing Attorney
Child Care Law Center
22 Second St., 5th Fl.
San Francisco, California

Happy, But He Shouldn't be Wet

Words cannot express the sorrow I feel for Marcia Todhunter and her family ("Wet, But Happy," February 1995). I don't feel this sorrow because Todhunter's son, Ben, has severe disabilities, but because the family has encountered a person who has the worst disability of all—intolerance.

My six-year-old son is still in diapers. I have met some very ignorant check-out clerks at our local retail store where I buy diapers, but the administrator in Ben Todhunter's day care program really takes the cake!

Even if this school program is not included as part of Ben's IEP, Todhunter still has a tool she can use on her son's behalf. It is the Americans with Disabilities Act (ADA). The ADA states that public accommodations, including child care centers, must make reasonable modifications in policies, practices and procedures to accommodate individuals with disabilities. Helping a child with toileting should be considered a reasonable modification. It sounds like the staff is willing to help this child; if so, they should stand up to the administrator and let her know she is wrong.

I am glad Ben is happy in this program and that he is doing so well, but he should not be wet.

M.P., Illinois

Thanks for "Hop On!"

We were thrilled and inspired to see Stephanie Royster's story ("Hop on!" March 1995). Like Stephanie, our three-and-a-half-year-old daughter, Kelly, also has spinal muscular atrophy (or Werdnig-Hoffman disease). Kelly got her power chair when she was three and quickly mastered it. It was wonderful to be able to show her another child who is in the same situation.

D.G., Michigan

Professional Praise

Although I am a professional (a teacher of children with severe disabilities), I find *Exceptional Parent* much more interesting and informative than many "professional" journals. Keep up the good work.

C.H., Florida

Fathers' Voices

I have really enjoyed the *Fathers' Voices* column in *Exceptional Parent*. It makes me feel more like a real per-

continued on page 8

Tell us about...

...your views on and experiences with various educational options (inclusion, special schools, etc.).

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son to see so many of my thoughts and feelings put into perspective. I certainly appreciate James May's efforts.

T.C., Nebraska

Inspiration for a Support Group

My seven-year-old daughter is beautiful, energetic and loving. A birth injury left her with moderate mental retardation, a severe seizure disorder, attention deficit hyperactivity disorder (ADHD) and sensory integration disorder. She was not diagnosed until the age of five because she has always been very healthy and in her birth records, the hospital neglected to mention that she was without oxygen for 15 minutes after birth.

I began reading *Exceptional Parent* when my daughter's disabilities were first diagnosed. A wonderful doctor gave me my first copy. It has been an excellent resource—very informative, even heartbreaking at times. I have yet to read an issue that doesn't bring tears to my eyes. The magazine has helped reduce my feelings of isolation, fear, self-pity and grief. It has given me the strength and courage to do what is necessary to improve the quality of life for my family.

We live in a rural area, about 70 miles north of Minneapolis. Resources in Minneapolis are inaccessible to us due to distance. I had been looking for a parent support group for two years but could not find one within a 50-mile radius of my home. After reading the September 1994 issue focusing on education, I was inspired to begin my own support group. I announced it in a letter to the editor of our local newspaper and our first meeting was held in October. Nine people attended—three parents of older children, four parents of younger children and two special education teachers in our school district.

Many professionals have offered their services to lead discussions of topics ranging from accessing services to dealing with feelings of grief and loss. We plan to form a sibling support group and organize social events. The school district has asked me to write an article about the group in their monthly newsletter.

I would like to help make your magazine more available to families in this community. I don't want to part with any of my issues because I reread them often.

J.L., Minnesota

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Throughout all the programs at Berkshire Meadows is a commitment to improving each young person's ability to communicate. For most of these young people, there has been no incentive to communicate: their basic needs have been provided for, in one way or another, and they have in any event been unable to express needs or wants in ways that other people understand. So the first task is to motivate communication, which we do by offering choices - of toy, snack, drink, etc. By using pleasurable choices and consequences, we provide even greater incentive to the child to break through his or her passivity.

In general, the Berkshire Meadows staff use Total Communication with all the students – that is, we use a combination of sign language, facial expressions and words. However, for many of our students using normal sign language is not feasible, so we develop individual augmentative communication skills. We teach the use of mechanisms such as object displays, switch-operated scanning devices and VOCAs (voice output communication aids) ranging from simple, pre-programmed devices to sophisticated computers with speech synthesizers. Once a system of communication has been established, we ensure that family members and all staff are trained to understand it, so that the student is spared the repeated frustration of not being understood.

Concomitant with learning to communicate is the ability to impact one's own life. For the youngsters at Berkshire Meadows, this is a primary step toward psychological development and emotional wellbeing. We believe that all children, no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, considered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

For further information, please contact: Gail Charpentier, Executive Director, Berkshire Meadows, 249 North Plain Road, Housatonic, MA 01236 (413) 528-2523

Circle # 10

SEARCH

Alpha-Mannosidosis; Telling a Child About her Disease

My 10-year-old daughter has been diagnosed with alpha-mannosidosis. This is one of the lysosomal storage disorders, progressive diseases in which a defective enzyme causes biochemicals (in the case of alpha-mannosidosis, oligosaccharides) to be stored—rather than metabolized—in the body. Alpha-mannosidosis is similar to mucopolysaccharidosis (MPS), but much rarer, affecting only a few hundred people in the U.S. There is no known treatment.

My daughter has been diagnosed with alpha-mannosidosis, type II, a "milder" juvenile form. Her immune system is probably affected; she is undergoing testing to confirm this. She also has a bilateral hearing impairment, learning disabilities, mild mental retardation and many physical difficulties.

I would like to hear from anyone who has information on alpha-mannosidosis, or who knows other families dealing with this disease. I would also like to hear how other parents have approached the delicate situation of explaining a disease like this to a child—when have you found it appropriate to do so, and how much information did you volunteer? My ex-wife and I have found it hard to agree on what to tell our daughter. I'd especially like to hear from other divorced parents dealing with this issue. How have you handled it, and how did it work out?

P.M., Georgia

Colorful Brace Stockinettes

My daughter is almost four years old and wears bilateral KAFO's (knee-ankle-foot orthoses). She uses "brace liners," cotton stockinettes that absorb perspiration and prevent the plastic part of her braces from sticking to her legs. Although young, my daughter is quite fashion-conscious and wants leggings in different colors. We've tried tights, but because the braces cover her thighs, tights make diapering/toileting difficult. Does anyone know a source for colorful brace stockinettes?

E.L., New York

Born Without Arms

My 18-month-old daughter, Kayla, was born with amblia of the upper extremities; in other words, she was born without arms. This is a rare physical disability occurring once in every 450,000 births. Experts believe Kayla's disability has no specific cause or origin; it just happened by chance.

I am looking for families who have a child with this or a similar disability who can give us insight and support. We would appreciate any correspondence.

P.B.A., Louisiana

EDITOR'S NOTE: SUPERKIDS NEWSLETTER (60 Clyde St., Newton, MA 02160) is a terrific publication full of useful information and stories from families and kids who have limb disorders like your daughter's. Subscriptions are free (two issues per year). To help families of children with similar limb disorders find each other, SUPERKIDS also publishes a directory; $12 for families, $17 for professionals (includes postage).

Partial Trisomy of Chromosome One

Our 16-month-old daughter has partial trisomy for a portion of the distal long arm of the first chromosome. Ashley was born with a club foot; a CAT scan showed that the corpus callosum portion of her brain did not fully develop. She currently receives physical therapy and speech therapy; most of her motor skills are at a six-month-old level.

The doctors tell us this is a very rare condition. We have been unable to locate any other children with this chromosomal abnormality. We would like to hear from anyone who has any information about this condition.

S.P. & S.P., North Carolina

Dealing with Seizures

My wonderful son, Christopher, is almost three years old. He scoots around on his behind and is just starting to stand by holding onto furniture. His speech is limited to cooing and babbling.

In July of 1993, Christopher had an MRI which showed that he had cerebral dygenesis; meaning roughly half his brain is gone. He has had a normal EMG, and an abnormal EEG. Chromosome tests have been normal.

Christopher has developmental delays, hypotonia (low muscle tone; mainly on the left side), slightly clubbed feet, farsightedness and a seizure disorder. His seizures are controlled, for the most part, by Dilantin. But now, when he does have seizures, he stops breathing.

Are there any other children out there like Christopher? I want to know how other parents deal with the seizures. In particular, how do other parents sleep at night? Christopher is on a monitor right now, but it's showing he has some apnea. I want to know how far this might go, and what we can expect. Right now we don't have many answers and it would be nice to know that we are not alone.

D.R., Wisconsin

Adams-Oliver Syndrome

I'm a 21-year-old mother in search of information on a rare genetic disorder known as Adams-Oliver syndrome, which involves congenital scalp, skull and skeletal defects. My one-year-old daughter was born with aplasia cutis congenita on the top of her head; this means that the skin in that area did not develop. That has healed over. In addition, her toes are very short.

My daughter's case is unique because she has severe brain damage—not typically associated with this syndrome. However, doctors say that her brain damage may be related to the syndrome, occurring as a result of deformities of the veins in her brain.

My husband and I have done as much research as we can. We know there have been only 40 cases of this syndrome reported since it was first diagnosed in 1945. Some of these cases included vascular deformities, but none as severe as our daughter's. We are looking for any information that may help us help our daughter.

E.L., Arkansas

continued on page 12

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Circle # 74

SEARCH

continued from page 10

Kartagener Syndrome

I am the mother of a five-year-old boy who has immotile cilia syndrome, also known as Kartagener syndrome, a genetic disorder characterized by chronic sinusitis and respiratory problems.

My son gets frequent respiratory infections and is often hospitalized to have intravenous antibiotics. He has asthma and a speech delay.

My husband and I have not found any other families dealing with this syndrome or many doctors who know much about it. We are looking for any information, and contact with other families to start a support group.

B.U., Michigan

Chromosome 10p–

We have a two-year-old son, Jake, who has been diagnosed with a P deletion of chromosome 10. Jake has a severe hearing impairment, multicystic dysplastic kidney disease and global developmental delays.

We are seeking information about the tenth chromosome—what information is stored there and what are the effects of a deletion? I want to hear from other families who have dealt with abnormalities involving chromosome 10.

J.S., California

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond, *Exceptional Parent*
209 Harvard Street, Suite 303,
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

RESPOND

Loud Noises in Public

G.W. & J.W. (December 1994) have a six-year-old daughter, Kaitlyn, with severe intellectual disabilities. Kaitlyn does not talk, but makes loud noises and high-pitched screams; her parents worry about how these noises will be handled when she starts kindergarten next year. They wanted to hear from anyone who has dealt with a child who has similar characteristics, and were especially interested in suggestions for getting Kaitlyn's noises "down to a reasonable pitch."

I began to write to you after reading your letter, but with our busy lives, I set my response aside and never finished it. I wish I had, especially after reading the response that was published in the March 1995 issue. D.T. from Texas, whose daughter also screams in public, said she and her husband had decided against forcing their daughter to modify her behavior—"These screams are [her] only means of communication… This is one area where society will have to make the adjustments." I'd like to offer another opinion.

Our son, Danny, will be five this summer. Like your daughter, Kaitlyn, he enjoys picking things up and dropping them. He also has a constant need to touch things and bring them to his mouth. Danny is unable to speak; when he becomes frustrated, he bites his shirt. He also screams a high-pitched scream.

Danny began screaming when he was a year old. As he got older, the screaming became louder and more frequent. I would have loved to have said, "Well, society can just deal with it;" unfortunately, society and our education system don't work that way.

Danny attends a special school that is part of the public school system. You can imagine how thrilled we were when his teacher told us he felt Danny was ready to attend a preschool class. We thought, "He's on his way now." He began the transition by attending this class every Friday for a month.

My heart sank when Danny's teacher told us that the preschool teacher felt Danny's screaming was disruptive to the other children; she was not sure he should attend her class full-time. I knew that by law, Danny had a right to attend her class. But why would I want someone teaching my son when she felt he was a burden?

On a routine visit to the doctor, Danny started his screaming. The doctor asked if this is what we had been telling him about for the past three and a half years.

I said it was.

The doctor said he wanted to try something. He turned Dan's chair to face him and used a strong tone to tell him that screaming was inappropriate behavior.

I was appalled. We had been going to this doctor for almost five years; he knew the screaming was Danny's only way of communicating. But then I realized that Danny had stopped screaming as soon as the doctor reprimanded him.

After that doctor's visit, my husband and I took a long, hard look at ourselves and the way we disciplined our son. We asked ourselves if Dan understood us. The answer was "yes." Then we asked whether we would allow our other three children to scream or make loud noises for no apparent reason. The answer was "no."

We realized we were treating Danny differently because of his special needs. So we began to give him a time-out every time he screamed, by putting him in a chair. This was very hard for us to do. Every time I placed him in the chair, my heart would break.

It's been four months since we started doing this. Now, Danny only screams once in a while. When he does, I can tell him that if he screams again, he'll get a time-out. Normally, he won't scream again. This also works in public. If I warn him, he'll stop. If he screams again, he gets a time-out. His teachers are amazed at the difference in his behavior. Very rarely does he scream at school because they also have a time-out chair.

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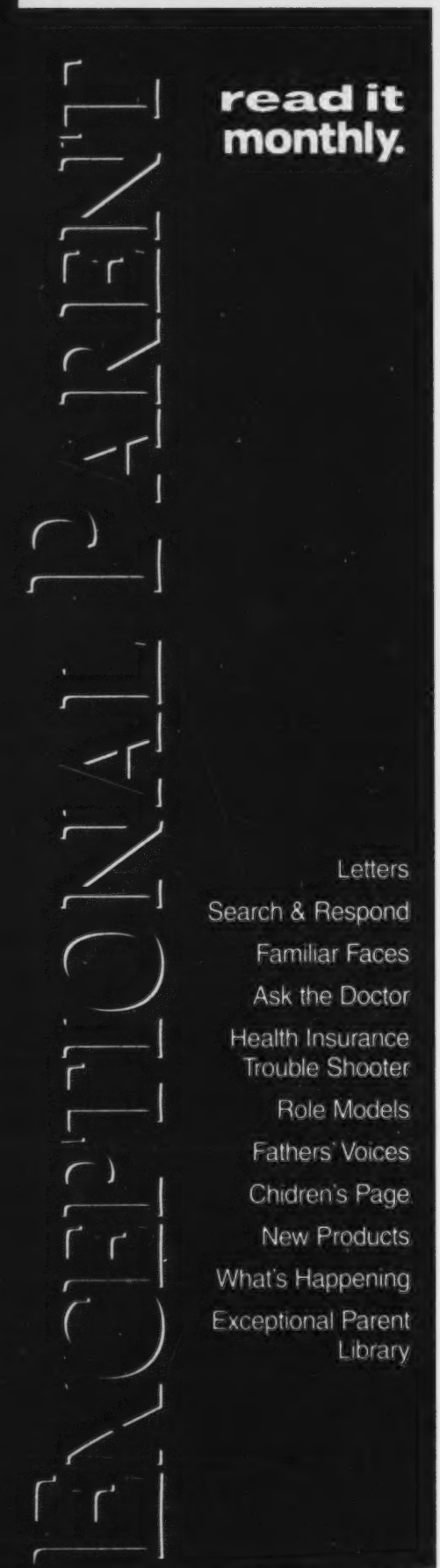

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read it monthly.

The best part is this: now that we no longer accept Danny's screaming as communication or as part of his disabilities, he has started to use sign language. He now signs "yes" and "no," and when he wants our attention, he uses appropriate ways of getting it.

This may or may not help you; every child and family is different. I don't know you or Kaitlyn, but I thought you might like another idea instead of just expecting others to accept her screaming. I love my son with all my heart and want all the opportunities in the world for him. I learned that by letting Danny scream, I was taking some of these opportunities away from him—opportunities to make friends, to communicate better with the people around him and to learn in a regular classroom. I don't feel like we made our son conform to society's standards, but that we taught him he must behave at home and in public in the same way we expect our other children to behave. He has grown from this experience, and so have we.

D.B., Michigan

Undiagnosed

D.N. (March 1995) was seeking a diagnosis for her three-year-old daughter's condition. Amanda was born with extremely low muscle tone, dislocatable hips and hypermobile joints. She began walking independently with the use of ankle-foot orthoses (AFOs) just before she turned two. Based on a muscle biopsy, doctors believe she has Duchenne muscular dystrophy. However, D.N. has doubts about this diagnosis because this type of muscular dystrophy is rare in females, is not evident at birth and leads to elevated creatine phosphokinase (CPK) levels—Amanda's CPK levels are normal.

I read your letter out loud to my husband. When I got to the part where you said "I have a strong feeling that one of the readers of *Exceptional Parent* has seen a child like Amanda," my husband sarcastically replied, "No, we've *never* seen anything like that..."

Two of our three children have a connective tissue disorder called Ehlers-Danlos syndrome (EDS). Has anyone considered this syndrome as a diagnosis for Amanda?

EDS causes extreme joint laxity and dislocations in some children. Brynthea, the first of our two children to be diagnosed with EDS, was tested for the disorder after I told her pediatrician that she would pop her hips and shoulders in and out at will to gross out her sister and brother. She was slightly delayed with sitting and crawling.

Good luck to you. It must be terribly hard to search for a diagnosis. It's hard enough having one!

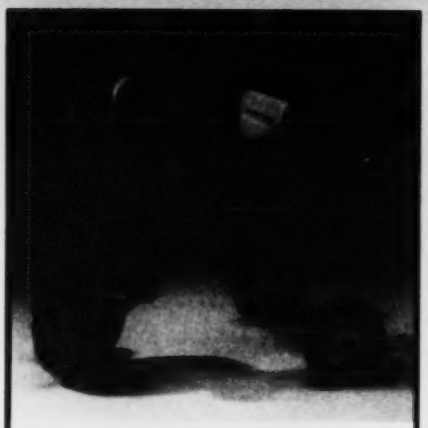
R.K., Pennsylvania

■ We saw our own experiences mirrored in the letter from Amanda's parents. Our son was born in May 1984 with low muscle tone, joint hypermobility and velvety skin. Like Amanda, he started walking after getting AFOs. Our doctors considered muscular dystrophy as a diagnosis, but he did not fit all the criteria. Finally, the genetics specialist decided to investigate a connective tissue disorder called Ehlers-Danlos syndrome (EDS). A tissue biopsy confirmed this diagnosis. There are about 15 different sub-types of this disorder. •

The Ehlers-Danlos National Foundation was established by Nancy Rogowski and her husband in 1985. This foundation is an enormous support for anyone who has EDS or knows someone who does. The foundation can refer Amanda's family to resources for diagnostic testing. If Amanda is diagnosed with EDS, they can put her family in touch with others in their area.

D.D. & M.D., Iowa

EDITOR'S NOTE: The Ehlers-Danlos National Foundation may be contacted at P.O. Box 1212, Southgate, MI 48195; (313) 282-0180, (313) 282-2793 (fax).



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Circle #223

Crisis

Poetry and photos by Galen Lowe

Take two aspirin and call me in the morning; life should be so simple. My ten-year-old son Brennen has a fever and is unable to swallow—swish and spit, swish and spit, over and over. This is new, something different. I call the doctor's office.

The nurse's voice sounds measured, reluctant to squeeze yet another patient into an already overcrowded schedule. "Well, if he can't swallow, I guess you'd better bring him in." Brennen is listless in the car; he staggers like a drunk across the parking lot and into the doctor's office.

I never imagined how sick a child could be. I never imagined I would hear a doctor saying, "The next few minutes will be critical. If we don't work fast, your son may die."

The next few minutes have stretched out for three years. We've seen times of crisis, as well as times of peace. Brennen had fallen prey to an infection that made his epiglottis, the skin-sized flap that closes when we swallow, swell up to the size of his thumb. He could not breathe without a tube running down his throat into his lungs. His mouth taped shut around the tube, he could not speak. Nights were hard. A sticky fluid began building up inside his lungs; a respirator was brought in to help him breathe. Scared, I wrote "Kites" at 2:08 in the morning while Brennen was lying awake in his hospital bed, exhausted, and trying to cough around his breathing tube.

Brennen spent two weeks in intensive care, recovering from that infection only to have his body's white blood cells rise up in rebellion against him. Leukemia—another year in and out of the hospital. Now, fortunately, chemotherapy, radiation, shots and a never-ending supply of pills have finally laid this beast to rest. Brennen is now six months out of treatment, and confident he'll never be back.

As parents of children affected by disability or disease, we face challenges that force us to reach deeply inside for resources we may not have known existed. For some, the challenge lasts a lifetime; for others, the experience plays itself out over a much shorter segment of time.

These poems are expressions of what it was like to be with my son in the hospital while he was living with the agony and frustration of cancer...

Brennen Lowe with sisters, Kelsey and Sierra.

Apples

If I have to go
back to the hospital again
to be with my son,
I'll always take my knife

Because there is never
anything sharp enough
in the parents' kitchen
to cut up the apples
that frustrate several
plastic knives before
yielding finally to
the blunt edge of a spatula
I find behind the
microwave.

When all I want
is a slice of normal life
like apples
in my cereal
for breakfast.

Nighttime on the Pediatric Floor

We
are the parents
who wait
unnerved

rocking and holding
waiting and hoping
our courage prevails

our dreams
reveal

a pearl
in place of
peril.

I Don't Feel

I don't feel
like doing anything
except the things
I need to do to survive.

I eat, sleep, dance
and look for comfort
in the presence of friends
I care for.

The rest of my world,
the part composed
of responsibilities,
is piling up around
me untouched

as mountains reaching
toward heights
I wonder
if I shall
ever breach.

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The Quilt

A Requiem

Whose hands will make the quilt
whose hands will lovingly stitch
the fabric, fold the cloth
color in details of the faces
long since gone, of our children
who died young, from cancer?

What field will lie covered
by great squares laid out
open to the mercy of a
fickle wind that may
at any moment crumble
our memories, as it has their lives?

Whose hearts will lie open in sorrow
disbelief at the premature
harvest of life
whose hands thrust deep into pockets
or held tight behind backs
will hold tears of sorrow
at the injustice of our loss.

This poem was written after viewing the AIDS quilt.

Just about to leave the hospital, Brennen is already thinking about his next ballgame.

Kites

When it hurts,
do you ever
try to think
of kites tied
not to tubes
but to strings?

And about how
one of these
strings, one slender
thread of white
against the blue,
dips down from

Above, lifting you
and your hand
up out of bed, calling
you to run free
to a place
where leaping
sideways

You can dance
laughing
in the shadow
of their tails?

Despite his many tubes, Brennen plays plenty of Nintendo.

(Clockwise from left) Kelsey and Galen Lowe, Janice Done Lowe, Brennen and Sierra Lowe and Julia Conti.

Galen Lowe lives in Southwest Harbor, Maine with his wife, Janice, and step-daughters Nikki, 13 and Julia, 12. Galen's children, Brennen, 13, Sierra, 7, and Kelsey, 15, live alternate weeks with Lowe and his former wife, Linden O'Ryan. Brennen's hobbies include soccer and competitive swimming as a member of the Mt. Desert Island YMCA swim team.

EDITOR'S NOTE: As EXCEPTIONAL PARENT was going to press, we learned that Brennan had suffered a relapse of leukemia. Doctors hope he will be able to undergo a bone marrow transplant in the coming months.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

Thomas Strax

Learning to stand

Thomas E. Strax, M.D. is medical director of the JFK Johnson Rehabilitation Institute in Edison, New Jersey. He is also a professor and department chair at Robert Wood Johnson Medical School and serves on the board of directors for United Cerebral Palsy of New Jersey. Strax, 53, graduated from New York University School of Medicine in 1967. He has a 24-year-old son and 25-year-old daughter.

The following was adapted from a recent interview between Strax and Andrea Kamens, an intern at EXCEPTIONAL PARENT.

I'm old enough to go back to a time when parents were overprotective and ashamed of children with disabilities. Children with disabilities did not attend school or play in the neighborhood. However, my parents had the radical idea that if I was going to exist in a hostile society, I should be integrated into that society as early as possible. My parents treated me like they treated my two able-bodied sisters—as a child who had to learn to become independent and not as one to be pitied or coddled.

I was born a mess. I was a breach delivery, with a prolonged stage 2, which means not enough oxygen reached my brain—a hallmark cause of cerebral palsy.

When I was growing up in Queens, New York in the 1940s, public schools did not admit "handicapped children." Although I don't know the details, my parents took the issue to court and I ended up at a public elementary school.

I was always around able-bodied children my own age. My mother started a Cub Scout den with neighborhood kids, and, when I was 11, sent me to a "normal" sleep-away camp.

Dr. Thomas Strax consults with attending physiatrist (rehabilitation specialist) Dr. Sara Cuccurullo at the JFK Johnson Rehabilitation Institute in New Jersey, 1994.

At camp, my counselor set up sports so that the team that chose me was never at a disadvantage. In baseball, I had a substitute runner. If I got tired on a hike, a counselor carried me on his back.

Fitting in

During my first day at Bayside High School, we had to write our family history on little cards. Since I couldn't write that small, I asked the guy next to me for help. It turned out that he became a class leader. When we became friends, I became one of those fortunate ugly ducklings who got into the "in-crowd."

I couldn't always rely on luck. When it came to dating, I had to hold my own. Once, I asked the best looking girl in camp to a dance. She said yes. What I didn't know was that all the other guys were drawing straws to see who would get to ask her. I got beaten up, but I had a great time at the dance.

Another girl I had dated asked me, after a good night kiss, "Can you have sex?"

I asked back, "Can you?"

Rules of life

Middle adolescence was a lonely time, because my friends had girlfriends and I did not. But, college was an equalizing experience.

Someone once asked my college roommate, "What do you do special for Tommy?" He said, "When Tommy falls down, I kick him." That may be facetious, but it's vital that children with disabilities learn the rules of life. Sometimes, that means letting them get hurt.

One reason it is hard for people with disabilities to get jobs is that becoming employable involves a tremendous number of social skills. If you haven't been able to grow socially with your peers, you can't make it as an adult.

To become an adult, you have to find your own identity. Able-bodied children do this by trying on different identities until they find one that fits. I did the same thing.

The family business

I always wanted to be a physician. There are 10 in my immediate family, most of whom went to New York University (NYU). My father, Selig Strax, is a famous surgeon; my uncle Phil won the Sloan Kettering Award for research in breast cancer—it's the family business.

It didn't always look as if I was going to make it though. When my parents first tried to get me into grade school, the superintendent said I had an IQ of 40 and should be institutionalized.

Physical issues were so pressing that, for a long time, no one knew where I was intellectually. My grades were C's and D's. In the early days, my report cards just marked me "present." Then, in high school, I grew into

physical maturity and began earning A's and B's.

When I applied to medical schools, reactions varied. During one interview, I was told, "How dare you waste my time when there are able-bodied people who want to get in!"

My first rejection came from Albert Einstein College of Medicine in New York. However, soon after, I received a call from the dean. He wanted to know why someone with cerebral palsy felt he could handle medical school. I told him; two weeks later, I received my letter of admission.

In the end, however, I went to NYU, following in my family's footsteps. To my knowledge, I was the second person with cerebral palsy to formally practice medicine.

Thrust into activism

Since becoming a doctor, I have also become an activist. I had no choice. I was one of the first children with disabilities to be mainstreamed in the New York public schools. In college and medical school, I was the only person with a disability on campus. I became a symbol, and people used me to decide whether or not to let others follow.

Sometimes, it makes me angry. It's easier to deal with a group as if they were homogeneous, but we're not. Each person should be evaluated as an individual and not by anyone else's success or failure.

In my field, a disability is sometimes seen as an advantage. Many patients believe someone who has a disability will be more empathetic about injury or illness.

However, I don't think I make a better physiatrist (a specialist in rehabilitation medicine) because I have a disability, any more than a woman makes the ideal gynecologist. You don't have to experience something to understand it, nor does experience guarantee empathy.

Not "handicapped"

In 1973, during a speech, I "defined" three words we often misuse—"impairment," "disability" and "handicap." I later helped write these definitions into the Americans With Disabilities Act (ADA).

Dr. Thomas Strax was named medical director of the JFK Johnson Rehabilitation Institute in New Jersey in 1985.

An "impairment" is something you don't have, such as full strength in your leg. A "disability" is something you can't do because of that impairment; you can't walk fast because of your weak leg.

A "handicap" has to do with functional need. If you are going to be CEO of a major corporation, walking slowly is not a handicap. If you're going to be a patrolman chasing down gangsters with your bad leg, then, you are handicapped.

In the 1970s, I was asked to appear in television commercials for the national United Cerebral Palsy Associations. I agreed, but demanded I be treated as a competent professional. I appeared as a doctor examining patients. It was the first major media commercial not to use the word "cripple" when describing someone with a physical disability.

Changing times

I've seen, and effected, a lot of changes in our society. I introduced reverse mainstreaming to JFK Medical Center's child care and pediatric rehabilitation programs so children with and without disabilities can learn and play together. I've helped students gain admission to exams and graduate programs by insisting they be judged on their individual merits, not their disabilities.

I hope I have gone from being "the only one" to being just the beginning. I am glad to see that today, many more parents are raising children the way mine did, to stand on their own. **EP**

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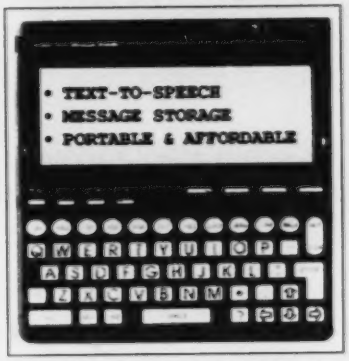

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Familiar Faces

Caitlin Hoel, 3, knows that riding her tractor in the front yard of her Baldwin, Missouri home is the perfect way to enjoy a sunny afternoon. Caitlin's mom, Tracy, remembers the day Caitlin, then eight months old, was diagnosed with Alcardi syndrome—"The doctor said she would never crawl or walk, and probably wouldn't live to her first birthday. She sure showed him, and us, too!"

This accomplished young equestrian is Jessica Lee Balzer of Buffalo, New York. Jessica, 7, has hypomelanosis of Ito with developmental delays. She is included in a regular first grade class and enjoys school almost as much as horseback riding.

Four-year-old Tyler Nakonechy lives in Grand Forks, North Dakota with mom Mickie, dad Perry and little sister Brenna. Mickie says that Tyler, who has cerebral palsy, is "a little boy of few words but many smiles—the biggest of which are saved for his daddy!"

The Telkamp kids enjoy a wagon ride near their home in Hawthorne, California. Seated in the wagon are (from left) Alex, 4, and Christopher, 2. Standing next to the wagon is Alex's twin, Julie. Alex has hydrocephalus, cerebral palsy and cortical blindness; he enjoys school, wagon rides and being told how very handsome he is. Christopher, who has autism, is a big fan of Barney the dinosaur and cheese puffs.

Michael Verdin, 3, prepares to follow his right shoe down the slide on his backyard jungle gym. Michael, who lives in Tulsa, Oklahoma, has tuberous sclerosis.

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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Saying it a Different Way

"Problem behaviors" may be a means of communication

by Judi Rosenstein and Jan Turner

Ashley's parents had come to dread dinnertime. Almost every evening, the family's meal was interupted by Ashley's kicking, screaming or throwing of silverware. Her behavior made it impossible for the family to eat at their favorite restaurant or go to relatives' homes for holiday dinners. Her parents were desperate for a "solution" to these disruptive behaviors that held them captive in their own home.

Ashley, a friendly two-year-old girl, has difficulty using and understanding language. Like most children who cannot use language to tell others what they want, Ashley has found alternative methods of expression. Unfortunately, Ashley's "words" include throwing toys, hitting, scratching or having a "temper tantrum."

Scolding doesn't work

Although it is tempting to simply scold a child whenever an inappropriate behavior occurs, this approach has its problems. Responding to a child's disruptive behaviors—even by yelling—often gives the child something he or she wants, like your attention. This may encourage the child to repeat the behavior.

There are other reasons why verbal requests or reprimands are often unsuccessful in helping children with communication problems improve their behavior. First, children who have difficulty understanding language may not understand a parent's words. Secondly, because a child with communication problems has difficulty using language, what a parent perceives as "problem behavior" may be the child's primary means of expression. It is difficult to eliminate a negative behavior if it is the child's only way to communicate a particular message.

What is the child "saying?"

Several steps are involved in determining the communication needs served by a negative behavior such as hitting, screaming or temper tantrums. Begin by identifying situations where the behavior most often occurs. Then, plan to watch for instances of the child using this behavior in these situations. While watching, note what happened immediately before the behavior began and what happened immediately afterwards. See if you can figure out whether the child "got" something as a result of the behavior—like attention or a second helping of a favorite food. Getting something you want as a result of using a specific behavior is sometimes called "natural reinforcement."

PHOTOGRAPHS BY DENNIS PAPPENOS

Children with communciation problems often need to learn alternative methods of expressing themselves; Byron tends to cry and have tantrums. Speech-language pathologist Judy Rosenstein teaches Bryon to indicate he wants to blow more bubbles by signing "more." Byron's mother and siblings are also learning sign language.

Once you have determined what the child is communicating with the problem behavior, you can try to teach more "appropriate" ways to convey the same message. Socially-acceptable alternatives might include gestures, pointing to pictures, formal sign language or the use of specific words or sentences. Appropriate professionals, such as speech-language therapists, can help you choose the best alternative(s) for your child. Whatever alternative or alternatives are chosen, it is important to make sure the child has the ability to use these methods, and that others can understand them. If possible, offering children multiple modes of expression usually increases their power to affect their world, and consequently, decreases behavior problems.

How does it work?

Let's see how this plan worked for Ashley and her family. Ashley's parents began by discussing the problem behavior with professionals who were already involved with their daughter—her teacher, a speech-language pathologist and a behavioral psychologist. As a team, they decided to focus on the problem behaviors of hitting, screaming and throwing things, because these behaviors always occurred together. Ashley's parents told the team that these behaviors most often occurred at mealtimes. After observing Ashley's mealtime behavior over the course of a week, her parents noticed that Ashley's negative behaviors often occurred after she saw her brother eating one of her favorite foods. Ashley's "tantrums" often resulted in somebody giving her a second helping of that food. Her parents also noticed that Ashley exhibited similar behaviors at other times, when she wanted toys that were out of reach or an object

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Timothy is learning how to follow directions. Today's lesson is "setting the table."

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someone else was using.

Ashley's parents decided that tantrums were her way of making requests. Other people had trouble understanding Ashley's unclear speech, but everyone responded quickly when she started hitting, screaming and throwing things. In a sense, Ashley's communication needs were satisfied with these behaviors.

Ashley needed to learn to make requests in a more socially-acceptable way. Because her speech was still unclear, the team decided to introduce pointing as a way of making requests. Her parents began this process by pairing the new way of asking for something (pointing) with the old way (tantruming). Whenever Ashley used a tantrum to make a request, her parents pointed to and named the object they thought she wanted.

By using words with pointing, Ashley's parents were trying to give her an example of the words she could use to make a request. Because Ashley rarely used words, or combined words in sentences, her parents used single words, such as "cookie" or "car." This language "model" was basic enough that Ashley could attempt to imitate it. And the pairing of pointing and speaking showed Ashley that both ways of requesting meant the same thing.

Next, Ashley's parents started helping her use the new way of making requests. If Ashley didn't try pointing before beginning her unacceptable behaviors, her parents moved her hand to help her point toward the object they thought she wanted. Then they named it and gave it to her. In this way, getting the object she wanted became a "natural reinforcement" for pointing.

At first, Ashley only pointed to objects when her parents prompted her to do so. Later, she began to use pointing without a prompt—though still not consistently. Once Ashley's parents were sure she understood this new way of making requests, they began trying to ignore her tantrums. They accepted any socially-acceptable attempt at making a request, and "reinforced" these appropriate behaviors by giving her the object she wanted.

Gradually, Ashley learned that she could get what she wanted by pointing or trying to talk, but not by using tantrums.

More power through words

Increasing Ashley's vocabulary, both the words she can understand (often called "receptive vocabulary") and the words she can use (often called "expressive vocabulary"), also gives her more options for communication. Over time, she will begin to use the words her parents say when they encourage her to point. She will learn that words are more specific than pointing, and, therefore, more powerful—especially with people who don't "read" her non-verbal signals as well as her family.

Positive changes

As Ashley has learned more appropriate ways to communicate her needs, her parents and teachers have seen a dramatic decrease in negative behaviors. However, because communication is still difficult for Ashley, she sometimes reverts to using disruptive behaviors when she is tired or under stress. At these times, her parents try their best to avoid "rewarding" these negative behaviors by giving her what she wants. Instead, they encourage her to try using a gesture or a word. **EP**

Judi Rosenstein, M.S., CCC-SLP is a speech-language pathologist at Kennedy Krieger Institute in Baltimore, Maryland. She evaluates and treats children and adolescents with communication disorders, and behavior problems and communication disorders.

Jan Turner, Ph.D., CCC-SLP is director of the Speech and Language Department at Kennedy Krieger Institute. She is particularly interested in language disorders associated with learning disabilities, and with the difficulties some children have in storytelling or conversational interaction.

Communication Problems

Communication problems, like behavior problems, can occur alone or along with movement, learning or emotional problems. In fact, behavior problems may be the result of undiagnosed or untreated communication problems. Children of any age may have communication problems or behavior problems, or both, although communication disorders more often are diagnosed in younger children. Communication difficulties that begin at an early age may persist as a child grows older, or a communication problem may become evident for the first time as older children face increasing communication demands with peers, at home or at school.

Many families may find that the techniques presented in this article will be helpful in resolving their children's behavior problems. Some families will be able to apply these principles on their own, while others may find it more beneficial to work with professionals. Experienced "outsiders" may have an easier time identifying problem behaviors and the situations that trigger them. In any case, it will be easier for a child to learn new communication modes if all adults involved with the child on a regular basis—including teachers and other professionals—are involved in the effort to teach and reinforce these methods.

Children whose actions are severe enough to cause injury to themselves or others need immediate professional help. Parents who are not sure about the seriousness of a child's behaviors should discuss the behaviors with medical or educational professionals.

Children who may need more elaborate or electronic communication systems can be referred to appropriate specialists for these services. (See "Getting Started with Augmentative Communication," page 34.)

—J.R. & J.T.

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TURN-TAKING: A Giant Step to Communicating

by James McDonald

Children learn to communicate by taking an active part in interactions, not by simply listening to adults, or being "taught" words. Staying in conversations is so natural for us that we don't think about it, but children with developmental delays often need a great deal of practice taking turns with movements and sounds, even before they start to talk.

Most babies learn reciprocal turn-taking (back-and-forth interaction between partners who respond to what the other does and says) through natural interactions with adults—exchanging funny faces and sounds, waving "bye-bye" and playing "peek-a-boo." Turn-taking soon becomes a lifelong habit.

But turn-taking can be difficult and discouraging for some children—especially if adults take most of the turns. Adults often find it difficult to wait for slower children to respond, but waiting is one of the most important ways to help children learn to communicate.

What children learn from turn-taking

Here are five important things a child can learn by taking turns:

• *How to initiate interactions.* Some adults have a tendency to start and to take over activities and conversations; this can cause children to become passive observers or followers. If children are encouraged to take the lead frequently, they will learn to choose their own activities and topics.

• *How to imitate others.* Children learn a lot by imitating, or attempting to imitate, what other people do. When we engage in back-and-forth interactions with a child, using motions, sounds or words, the child feels motivated to imitate.

• *How to respond creatively.* Although learning to imitate is important; children will enjoy interactions more if they feel free to respond in their own ways, without fear of failure or criticism. A child's actual responses are not nearly as important as the fact that he is getting practice taking turns and learning to prefer being with people more than with things.

• *How to use actions in useful and meaningful ways.* Before they learn to talk, children need a lot of practice trying out different actions and sounds. Turn-taking interactions give children opportunities to try out new actions and sounds.

• *How to keep interactions going.* Often, children with developmental

Becoming Andrew's Playmate

Until he was three years old, Andrew was an isolated and physically defensive child with autistic characteristics. He communicated only with screams. I hoped he would learn better communication skills once he got to school.

During a chaotic first year of preschool, we were able to find ways to help Andrew stay calm. However, he still didn't interact with other people, and his communication skills didn't improve.

Then I learned how important it was to play with Andrew in ways he could play. I wanted Andrew to learn to take turns, and I started by imitating his actions. Resistant at first, Andrew eventually began imitating me and enjoying our contacts.

I had never thought about all the little things Andrew did; I just wanted him to talk. But I was starting to realize that Andrew's every sound and movement could be an important step in learning to communicate.

We took turns making funny sounds and body movements. When watching TV, we'd point and squeal at the Muppets and other "friends." In the kitchen, we'd take turns getting a drink or putting away silverware.

Once I realized that Andrew would not learn to communicate unless he interacted more with people, I started trying to keep him for "one more turn" when he started to leave me. He began staying longer; in fact, he started coming to me to initiate our play.

After a lot of work, Andrew got the idea. He chose to be with people more often. After being alone for so long, he was finally interacting.

Now, Andrew is so much more fun to be with. Andrew, now four and a half, is just starting to talk. But he didn't start talking until I forgot about teaching him to talk, and just started playing back and forth at every opportunity. I had to become his playmate, not his teacher or therapist. I would advise other parents to do the same—have fun, and let your child teach you how to slow down and appreciate things for what they are.

—Pam Rodawalt
Columbus, Ohio

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delays interact only briefly before being distracted by another activity or object. However, to become real communicators, children need to learn how to stay in interactions. As a first step toward communication, learning to enjoy people is more important than learning to make sounds and words correctly. The best way to help children learn this is to show them that playing and interacting with us is fun, not work! When adults become partners—rather than "directors" or "instructors"--children learn that their actions are important and often find ways to keep interactions going.

Turn-taking strategies

Any action or sound a child makes can become an interaction or communication. By responding to a child's seemingly meaningless behaviors, we can

"Get up! Get up!"

Barbara Cook with grandson Marcus Moore, 7.

Since I've learned how to play and talk with my seven-year-old grandson, Marcus, he's beginning to communicate with me much more. Marcus, who I am raising, has Down syndrome and is just starting to talk in words we can really understand. It's so exciting!

I began interacting more with Marcus after I learned to "match and wait," a technique in which I say something, then wait for Marcus to imitate me before I do anything else. He usually repeats what I say, but he's also starting to initiate more on his own. Last week, he came into my bedroom and said, "Get up! Get up!" This was the first time he had ever done this, so, of course, I got up.

I wish I would have learned about matching and turn-taking when Marcus was younger; I think he would be doing much more now. Now, I "match and wait" in almost everything we do together.

Marcus likes to help me wash dishes. When I say things like "dirty dishes," "wash, wash," "rinse cup" and "all clean now," he imitates me.

I also imitate Marcus' actions a lot when we play together. He still plays like a younger child, so that's what I do. He likes to throw stuffed animals at me in a little back-and-forth game, so I throw them back and say "good throw," "duck down," "missed" and "cheating!"

I've learned that any game can turn into a conversation if you just become part of your child's world.

—Barbara Cook
Bellefontaine, Ohio

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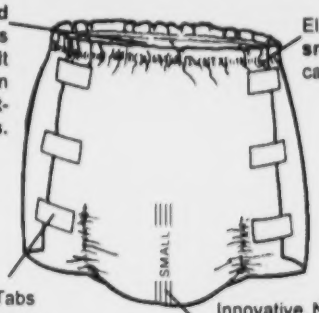

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Circle #14

Making Turn-taking Fun

Finding ways to take turns is fun and easy, once you get in the habit. I've learned three things about turn-taking: first, watch what your child is doing and become part of it; second, keep the interaction going for awhile; and third, make it fun!

This morning at breakfast, my son, Mark, a five-year-old with Down syndrome, was pretending to read the back of the Cap'n Crunch box. I peeked around the box and said "Hi!"

He poked his head out and said, "Hi!" back.

The game had started. We made funny faces, growls and roars back and forth with each other as he looked at me from one side of the box, then the other.

Here's another game we've played with words. One day, Mark called me Barbara. This was the first time he had done that, and it was a real surprise. I looked at him—just a little sternly—and said, "Don't call me 'Barbara.' Call me 'mama.'"

He repeated "mama," then said "Barbara" again.

Then I knew how to make a turn-taking game of it. I changed my words a little and said, "Don't call me 'Barbara!' Call me 'mother dear.'"

Well, of course, he repeated "mother dear," then said "Barbara" again, this time with a big grin.

What a game! We went through "sweet mama," "pretty mommy," "skinny mom," "smart mama" and just about everything else I could think of. He loved it! Even after we ended the game, he would sneak up behind me and say "Barbara," just to start it over again.

We don't play this game much anymore and I miss it. But all the funny faces, silly sounds and word games have served an important purpose for Mark's development—our days are now one long conversation.

–Barbara Mitchell
West Liberty, Ohio

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make these behaviors interactive. The more we enter our child's world and wait for the child to participate, the more likely it is that his actions will become social and meaningful.

Whether your child uses actions and sounds to communicate or is already beginning to talk in sentences, you can help the child take turns by making a habit of the following strategies:

• *Keep your child interacting with you.* Don't wait for play times to teach your child about turn-taking. Interactions will be more enjoyable for both of you when they occur naturally and spontaneously throughout the day. Try to have many little back-and-forth exchanges with your child during all your normal activities. The more practice your child gets and the longer he stays interacting, the more he will learn about communicating. Try to keep your child interacting with you just a little longer each time. You can do this by making interactions fun.

• *Balance turns.* This means you and your child each get the same number of turns. Give your child your complete attention and the time he or she needs to do something—this will help the child feel successful and self-confident.

Try to avoid question-and-answer routines in which you simply ask a child to label pictures or objects—"What is this?" "doll;" "What is this?" "bunny." Boring routines won't help a child learn creative, spontaneous turn-taking. Instead, add variety to your turn-taking by using different actions, sounds and words that your child can do and say.

• *Act and communicate like your child.* The more you "match" your child's actions and sounds, the more he will learn from you. If your child doesn't speak yet, you can copy his or her movements, sounds or gestures. If your child is beginning to talk, use the words he or she knows how to say. When we act and communicate like our children, they stay in the interaction longer. That gives us the chance to show them the

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Seven Years of Turn-taking

Our daughter Laura spent the first year and a half of her life in the hospital after being born with multiple complications. When we brought her home, she was on a feeding pump. She did not speak and had very little physical movement, but she always appeared to be observing the world around her.

When she was about three, Laura was able to begin outside therapy and preschool—always accompanied by a nurse or me. Finally, our family began to think about the future. A friend referred us to Jim MacDonald's clinic.

We arrived at Jim's office—Laura, Grandma, me, a feeding pump, a suction machine and oxygen. While we waited for Jim, I talked to Laura, shaking rattles in her face, trying to "stimulate" her. I wanted to make a good first impression.

As Jim walked into the room he said, "Would you please quit talking." I was offended and shocked.

But then I watched as he began interacting with Laura on the most basic level. If Laura moved her arm, he moved his arm in exactly the same way. If she glanced at something in the room, he followed her gaze, using single words to comment on what they were looking at. Laura never took her eyes off of him.

Over the following months, Jim taught us about turn-taking, matching and waiting. This involved adjustments for the whole family. Not only were we dealing with a child who had multiple disabilities, we were also learning to communicate with her in new ways.

It was hard for me to learn how to play with my daughter. My definition of play was "do, do, do; teach, teach, teach; stimulate, stimulate, stimulate." But I was doing all the "doing, teaching and stimulating;" I was trying to teach Laura things like colors, and she was just sitting there. Laura was not communicating with me, and I was frustrated and discouraged.

It took a long time for me to reach Laura's communication level and feel good about it. However, once I did, I began getting responses from Laura. She started to imitate me, and her eyes glistened with delight while we played. She began making very basic sounds, which I would repeat. Eventually, I started adding syllables. Laura was starting to communicate with us, and we understood her.

I also learned the importance of waiting. In my earlier interaction style, if Laura didn't respond quickly, I would either tell her the correct response or move on. By waiting, I began allowing Laura the time she needed to respond.

Laura, now 10, is in a regular classroom with supports. She has a delightful sense of humor, independence and fairness, and she *always* has something to say. Laura still struggles with finding the words, but if we wait, she always comes through.

—Jan Daily
Worthington, Ohio

Laura Daily (right) enjoys playing with best friend Marlene Moore.

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"It's your turn, David." "What's the matter?" "Do you want pizza or a hamburger for lunch?"

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Circle #3

COMMUNICATION

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next step they need for their development.

• *Wait, signal and expect.* Children need to participate in order to learn—it is not enough to listen to us talk. If an adult does not wait, the child misses his or her turn. Use a look of genuine anticipation to show your child that you expect something. If the child doesn't know what to do, you can point or physically help the child to take a turn. However, often, just waiting will elicit much more from a child.

• *Imitate and animate.* If you feel that you don't know how to play and communicate with your child, imitating the child's actions and sounds is a good way to start a turn-taking interaction.

Practice taking turns with no pressure to teach any particular skills. A child will stay with an interaction longer and do more when you make no demands other than keeping him there. Keep track of just two things—how long he stays and new things he does. Make those your rewards!

When adults say, "I can't think of what to do with my child," we reply, "First look at what he is doing. Then follow his lead, and then do something that keeps him doing his things with you." **EP**

James McDonald, Ph.D, C.C.C., is associate professor of speech and hearing science and director of the Parent-Child Communication Program at the Nissonger Center, both at The Ohio State University in Columbus, Ohio. The authors of the stories accompanying this article are participants in Dr. McDonald's program at the Nissonger Center.

Dr. McDonald is the author of BECOMING PARTNERS WITH CHILDREN *(Riverside Press, 1989) and is the editor of* COMMUNICATING PARTNERS, *a quarterly newsletter for parents of children developing language. (Subscriptions are $15 a year;* COMMUNICATING PARTNERS, *P.O. Box 141306, Columbus, OH 43214.) This article was adapted from the Summer 1994 issue.*

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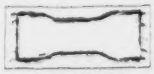

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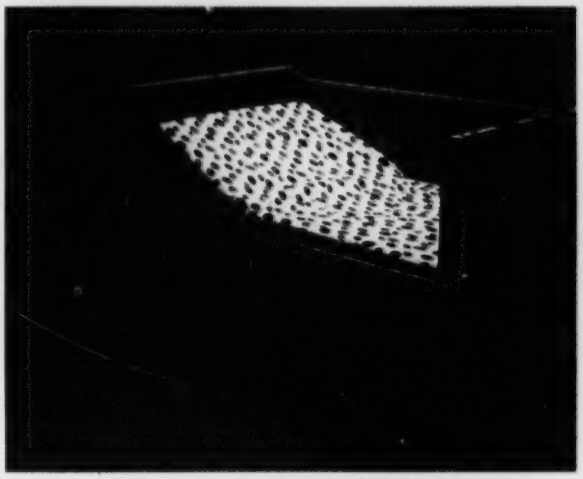

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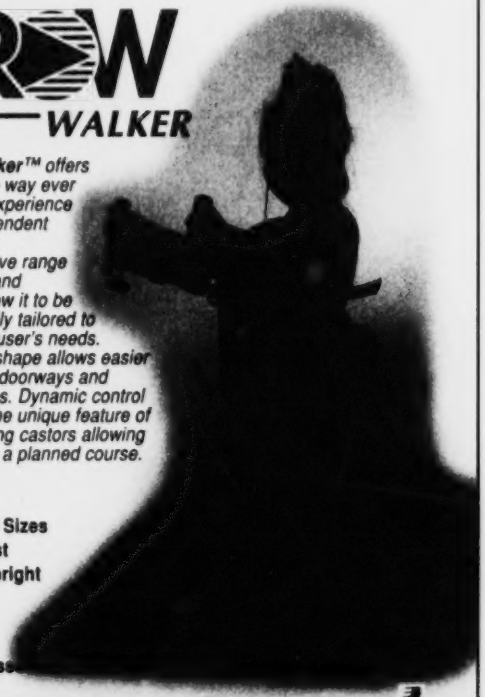

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Circle #11

Hearing Impairment & Hearing Aids

by Joseph P. Pillion

From birth to age five, children are on the "fast track" for acquiring speech and language. As infants and young children build communication skills, they also build stronger and more meaningful relationships with their families. Surrounded by examples of speech used to refer to everyday objects and activities, children learn to produce the same speech sounds to express themselves.

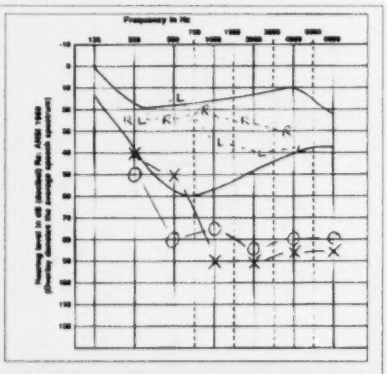
Learning to talk and understand others, then, depends heavily on the ability to hear. For young children whose speech and language development has not kept up with their peers, hearing testing is especially critical. If a child with a hearing impairment receives help and good auditory input at an early age, he or she will have a better chance of learning to use speech and language successfully.

Evaluating hearing

A child's auditory function should be evaluated by an audiologist, a professional who measures hearing and can fit people with different equipment to enhance their hearing. Infants and children from six months to two years of age are tested with a technique known as visual reinforcement audiometry. In this test, the child is exposed to animated toys that appear in a window as sounds are presented through a speaker or earphones. The child's hearing can be tested once the child has learned to anticipate the toys' appearance by turning toward the window whenever he or shes hears a sound. Older children may be asked to place pegs in a pegboard or blocks in a bucket when sounds are heard.

Special test procedures can be used with infants or older children who are unable to make voluntary responses to sound. For example, auditory evoked potentials (AEPs) use a computer to measure the brain's response to sound. AEPs—which require that the child be asleep or under light sedation—use electrodes taped to the scalp to measure the brain's electrical activity while sounds are presented.

One component of an AEP evaluation is the auditory brainstem response (ABR) or brainstem auditory evoked response (BAER). Audiologists can use ABRs to assess the hearing of even newborn infants. Any infant at risk for hearing impairments—those with a family history of hearing impairment, very low birth weight, cleft palate and/or certain developmental disabilities—should be tested.



This is the audiogram of a child with a bilateral, moderate-to-severe hearing loss. Frequency of the sounds (pitch) appears across the top of the graph; intensity (loudness) appear along the side. The shaded region of the graph shows the typical frequency and intensity of conversational speech. The audiologist has plotted this child's responses to sound with red circles (right ear) and blue X's (left ear).

Without hearing aids, this child hears very few speech sounds. However, with hearing aids—shown as "R" and "L" (for right and left ears)—the child can hear most sounds in a typical conversation.

Types of hearing loss

Each sound can be characterized by its pitch, or "frequency" (measured in cycles per second—Hertz, abbreviated as "Hz") and by its loudness, or "intensity" (measured in decibels, abbreviated as "dB"). Most speech sounds fall between 250–4000 Hz. Conversational speech is usually at about 60 dB in intensity.

During a hearing evaluation, the audiologist plots the quietest sound that an individual can hear at each frequency on a graph called an "audiogram." As viewed on an audiogram, hearing losses may have different shapes. One child may only have trouble hearing high frequency sounds, but hear everything else normally. Another may miss only low-intensity or quiet sounds, but hear fairly evenly across all frequencies. These two listeners would hear the same speech differently. The first child might not be able to hear specific high-frequency speech sounds like "f" and "s," while the second may be able to hear all the speech sounds—but only if they are loud enough. Individuals can have either type of hearing loss, or a combination of the two.

Amplification

Boosting hearing level is called "amplification." When a child's hearing is not within a normal range, parents and professionals work together to decide if amplification will improve the child's ability to understand and use speech. An audiologist will try to provide a hearing aid that will allow the child to comfortably hear the full range of speech frequencies and intensities.

Sensorineural hearing impairment, which involves damage to the inner ear or the auditory nerve, may have an adverse effect on a child's perception of loudness. A child with this type of hearing loss may perceive barely detectable sounds as uncomfortably loud. The audiologist will try to solve this problem by adjusting the aid to control the maximum possible sound produced by the tiny speaker in the hearing aid—also known as the aid's "output." Hearing aids also include circuits that permit audiologists to adjust the output to provide more amplification in the frequency region where the child has the greatest amount of hearing loss.

A variety of amplification devices are available. However, audiologists generally prefer behind-the-ear hearing aids

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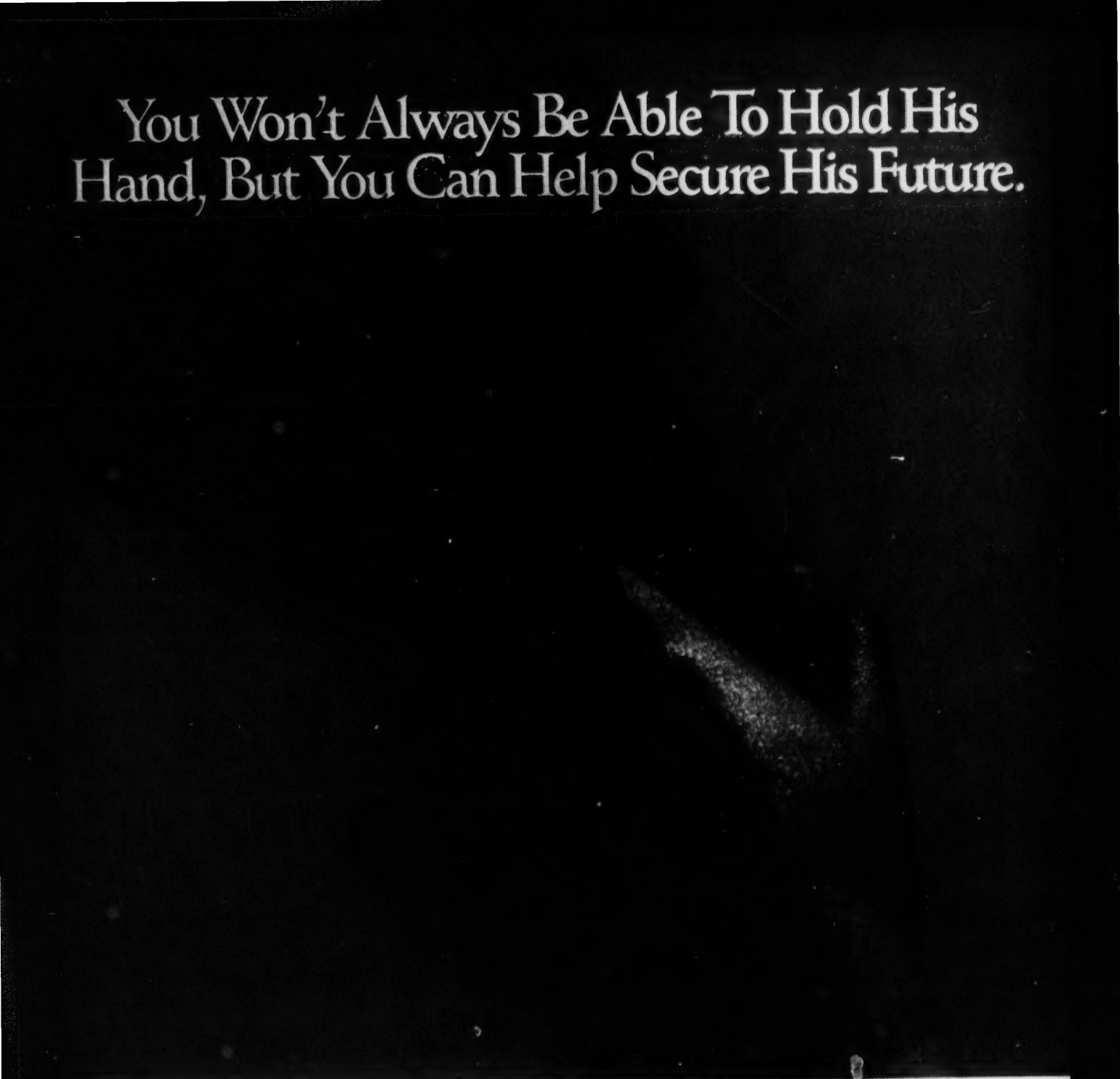

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for young children because they can be fine-tuned more easily as additional information about the child's hearing loss becomes available, or if a child's hearing changes over time. Because infants and toddlers grow so fast, in-the-ear and canal-type hearing aids are not typically used—as a child grew, the instruments would need constant re-sizing. With behind-the-ear hearing aids, only the earmold needs to be replaced as a child grows.

Assistive listening devices may also be available in public places. These include FM systems (like small radios) and infrared listening systems, which use the same kind of signal used in TV/VCR remote controls. Designed to overcome the effects of background noise, these devices—common in theaters, churches and schools—transmit a speaker's voice directly to a listener's headphone.

Because of noise levels and bad acoustics in many classrooms, background noise can be a big problem in school. Acoustic ceiling tiles and wall-to-wall carpeting can improve acoustics dramatically. If necessary for a child, these classroom modifications, as well as classroom use of an assistive listening device, should be included on the child's IEP.

In a visual reinforcement audiometry test, children may be asked to place pegs in a pegboard whenever a sound is heard.

Hearing aid maintenance

Hearing aids worn by an active toddler are subjected to considerable wear and tear. Because a hearing aid is worn on the body, moisture may affect its delicate electronic circuitry. Hearing aid dehumidifier kits help prevent this type of damage.

It is important to monitor a child's hearing aid(s) on an ongoing basis to ensure optimal functioning. This includes daily battery checks and listening checks using a hearing aid stethoscope that can be purchased from an audiologist. Every three months, have the audiologist take standardized measurements of hearing aid performance. Most hearing aid manufacturers provide a one-year insurance plan for loss or damage. Extended policies can be purchased through the manufacturer or a third-party insurance provider.

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Limitations of hearing aids

Parents and professionals should be aware of the limitations of hearing aids. In addition to speech, hearing aids amplify other sounds, such as environmental noise. When amplification is sufficient to amplify speech, "background noise" may interfere and be bothersome to the hearing aid user.

Some children may have such severe hearing impairments that they are able to receive only limited benefit from hearing aids. In such cases, hearing aid use may only provide a child with awareness of environmental sounds like car horns and smoke detectors, or access to certain features of speech, such as changes in loudness or pitch, which may add clues to lip reading.

If a hearing aid is not sufficient to allow a child to develop speech and language, other communication options—such as sign language—should be explored. Cochlear implant surgery is another option that could be discussed with an otolaryngologist (an ear, nose and throat doctor). Cochlear implants have been very controversial within the deaf community. Although some profoundly deaf individuals have become able to discriminate conversational level speech remarkably well after receiving cochlear implants, others receive far less benefit.

Behind-the-ear hearing aids are the most common form of amplification prescribed for toddlers and younger children. As the child grows, only the earmold will need replacement.

Providing hearing aids to a young child is a critical first step. But children with hearing impairments also need early intervention—including language stimulation—during their primary language-learning years. Auditory training can help new hearing aid users learn to pay attention to auditory signals, to recognize differences between auditory signals and to associate meaning with sounds.

For more information, or referral to resources in your area, contact the American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852, (800) 638-8255 (V/TTY), (301) 897-5700 (V/TTY), (301) 571-0457 (fax).

Joseph P. Pillion, Ph.D., CCC-A is a senior audiologist at Kennedy Krieger Institute in Baltimore, Maryland. He has been with the institute for eight years and specializes in audiological management of children with brain disorders.

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Circle #224

Getting Started
with Augmentative Communication

by Naomi Angoff Chedd

"You're hungry? You want something from the cabinet...you want a cookie...a chocolate cookie? No. A graham cracker? No. Hmmm...a granola bar? Yes!" I breathe a sigh of relief; I figured it out fairly quickly this time.

My conversations with my four-year-old daughter, Kinsey, who has cerebral palsy and is not able to talk, often proceed along these lines. Using a combination of pointing, facial expressions, vocalizations, some simple signing that others would be hard-pressed to understand and my knowledge of her preferences, she can tell me what she wants. Most of the time I understand her, but it can be a struggle.

Is this the only way for us to communicate? Wouldn't it be more effective and satisfying if Kinsey could tell me right off the bat, "Mom, I want a granola bar. And how about some milk to go with it?" I often feel frustrated and impatient, and Kinsey obviously does too; she has a lot to say and only limited means of expressing herself. For Kinsey and many children like her, augmentative communication (AC) is a solution—possibly the only solution.

Defining augmentative communication

"AC always involves a voice synthesizer," one parent told me.

"Don't you need to be able to use a computer?" asked another.

"I thought it referred to those picture boards kids in wheelchairs use," responded a third.

AC is all of these things and more. It involves everything—pictures, sign language, computers, voice output devices, letter boards—that supplements or replaces speech.

Although many children will move from non-electronic communication devices to computers, most will use a combination of AC methods. A child may use a computer and voice output device in school, but use a picture notebook, vocalizing and/or signing at home.

No one way fits every situation and every child. The challenge is finding the right combination of solutions to provide *your* child with the fastest, most effective means of attaining his or her goals. And no matter what features a system has, remember that the only good communication system is one your child will use.

Although experts have varying opinions on how and when to design an AC system, they *all* agree on one thing—using an augmentative system will not inhibit speech production. Howard Shane, of the Communication Enhancement Center at Boston Children's Hospital, says AC often leads to improved speech—"It takes the pressure off kids. They can relax, and speech may come more easily." Shane added that for some children, "learning occurs using a visual modality, so picture systems can actually speed up speech and language acquisition." Also, success with other modes of communication motivates the child to experiment with all available means.

Working with Edith Thayer, speech and language clinician for the Vineland School District in Vineland, New Jersey, William Troolin learned to communicate using his DynaVox within a few days. William, 16, has spastic quadriplegia, which limits his speech and movement. Photo courtesy Sentient Systems Technology.

Low-tech options

Preschoolers often begin AC use with situation-specific picture or symbol boards illustrating activities, chores, foods, toys, emotions, friends and family. These help a child get used to making choices, expressing feelings and telling stories.

Large vocabulary picture books are divided into various sections and contain categories such as people, places, action words, leisure activities, movies and toys. Professionals should design a communication book, but parents and teachers can participate in the process.

Electronic devices

It would be impossible to describe every one of the wide range of electronic products, but they include:

- Small, hand-held keypads, with various options including screen displays, printout and voice output (requires direct selection, meaning the child selects options with a single finger);
- Hand-held picture display devices with voice output (also requires direct selection);
- Programmable keyboards of various sizes, with or without

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voice output (can be used with direct selection, single switch use or scanning;
• Electronic picture communication books that fit into three ring binders and have voice output devices; and
• User-programmable devices (using direct selection or scanning), some of which include an auditory scanning function for users with visual impairments.

Home computers can be used as AC devices, and may be adapted to provide many selection options. These include touch screens, expanded keyboards and overlays requiring a lighter, less precise touch.

Pointing and typing aids, such as headsticks, mouthsticks, handsplints and optical lightbeam devices are also available.

The right system

Integrating an appropriate communication system into everyday life can be one of the major problems for children and parents. In my house, for example, we have 20 minutes to get breakfast ready, snacks made and two kids off to school. Selecting breakfast choices from a picture book would certainly help my daughter improve her symbolic communication skills, but sometimes it's easier to ask a question and get a nod of the head in response.

Jude O'Hara learned new things about her six-year-old son Stephen, who has cerebral palsy, after he started using a communication book. For example, the communication book, which contains alphabet and number pages, gave Stephen his first chance to demonstrate his spelling and math skills. Steven's family is now exploring ways for him to access a computer system, which he will need for writing, homework assignments and conversing with friends.

Alexander Freeman, 7, spells words using an Intellikeys keyboard and pointing device that was designed and constructed by a family friend. Occupational therapist Carrie Larson helps Alexander maintain his balance by holding his right hand down on the desk.

Linda Freeman, the mother of Alexander, a seven-year-old with cerebral palsy says therapists, AC experts, computer programmers and hardware designers have been working on developing a communication system for Alexander since he was two. "Alexander actually has one, but it's so difficult and time-consuming to use and has so many bugs that nobody wants to go near it. It frustrates him and everybody else," Linda says. "And it wasn't for lack of trying. Our team was creative,

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Circle #138

COMMUNICATION

continued from page 35

hard-working and committed to providing Alexander with a system he could happily use. But after spending all that time and money, we're starting again from square one."

Unfortunately, the Freemans' experience is not uncommon. One of the major problems they faced was that when Alexander's system was first beginning to take shape five years ago, the technology was fairly new and there were a lot of hardware and software problems. But whenever technology is central to a system's success, keeping up with the latest and best products and techniques will always be a challenge.

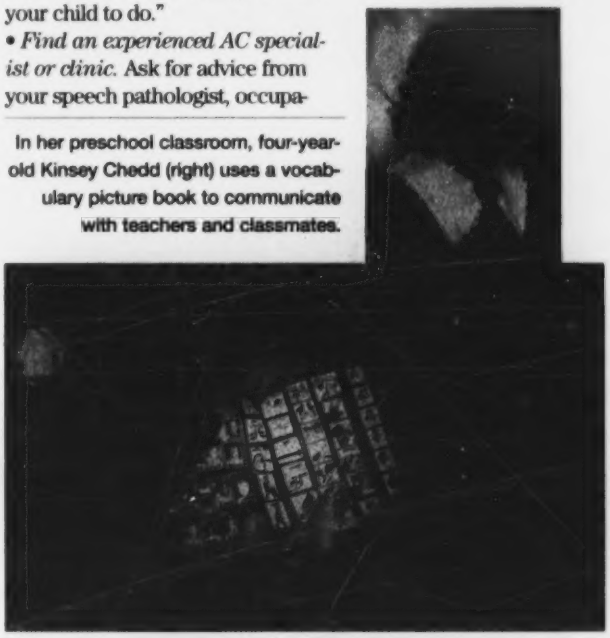
How to get started

• *Determine if your child is a candidate for augmentative communication.* AC can be used by anyone whose speech cannot meet their communication needs. Even if a child's family understands his or her speech, AC can provide a means for the child to interact with friends, teachers and other important people.

• *Set specific and realistic goals.* For a preschooler, making activity choices and friendships might be the best use of AC; an academically competitive fifth-grader might need a system that allows for quick response in class and provides a means of talking on the phone.

• *Integrate pictures into everyday conversations with your child.* This doesn't mean using a picture to communicate every noun, verb or adjective. But if you're going to McDonald's, for example, hold up a ketchup packet with the McDonald's logo. If you're going to see Grandma, point to a picture of Grandma. Says one AC specialist, "You can't talk to a non-verbal child using only words and then expect him to respond using only pictures. You need to model what you want your child to do."

• *Find an experienced AC specialist or clinic.* Ask for advice from your speech pathologist, occupa-



In her preschool classroom, four-year-old Kinsey Chedd (right) uses a vocabulary picture book to communicate with teachers and classmates.

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tional therapist (OT), physical therapist and other parents. Try to work with clinicians that are in it for the long haul; you'll need them.

• *Get good language, vision, hearing and OT evaluations.* Clinicians, especially OTs, can often provide valuable advice on positioning, system access and maximizing hand and eye use. Be sure they are involved from the beginning.

• *Become an informed consumer.* Product descriptions often make communication devices sound miraculous. Before purchasing anything, be sure you know how it works and what it can do. Talk to users and observe a variety of systems in action. Many manufacturers run seminars and workshops at trade shows. Most offer rentals as an alternative to purchase and some may let you borrow devices to try them out.

• *Ask for help and cooperation from the school.* Find someone with experience in designing AC systems or ask for outside consultation. "It is often the classroom aide who is the critical link and makes the difference between success and failure with an augmentative system," Shane says. "This is the person who knows your child the best and has the strongest commitment, but is the lowest paid and has the least training. I would like to see that change."

When I explained my daughter's capabilities and needs to a number of experts in the field, I received a variety of perspectives and information. I asked when I should begin to get more aggressive with AC, and perhaps the most useful advice came in the form of a question—"She's already four? What are you waiting for?" **EP**

Naomi Angoff Chedd lives in Brookline, Massachusetts with her husband, Graham, a filmmaker and television producer, and children, Harry, 5, and Kinsey, 4. Naomi is a freelance writer and graduate student in counseling psychology. She writes a regular parent column in the NDT Nework, a newsletter for therapists, published by the Neuro-Developmental Association, and is a new member of Exceptional Parent's editorial staff.

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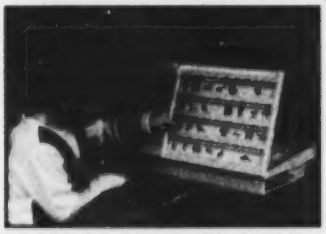

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Circle #59

FACILITATED COMMUNICATION: What Parents Should Know

by Karen Levine and Robert Wharton

Communication—the ability to express one's thoughts, ideas and wishes to another person—is a vital component of life. However, when a developmental difference, such as language delay, motor impairment, developmental delay or autism, interferes with communication, a child needs extra help.

There are many approaches to enhancing a child's communication skills. Some children can benefit from speech therapy; others may learn to use gestures, signs or augmentative communication systems. In the last five years, facilitated communication has received publicity as a possible breakthrough in communication.

What is facilitated communication?

A six-year-old boy with autism sits in his classroom next to a teacher. Until recently, the boy was considered developmentally delayed. He cannot say any words but seems to understand a few spoken phrases. In front of the boy and his

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An FC Nightmare

My husband and I were introduced to FC by a police detective, who told us our 13-year-old son son, Josh, had made allegations of sexual abuse against a family member. The detective gave us typed transcripts our son was supposed to have produced at school when "facilitated" by his teacher. We had no idea Josh's teachers were using FC with Josh, who has moderate mental retardation.

We took Josh for a physical. We felt somewhat reassured when the doctor reported no physical signs of sexual molestation. But that reassurance was soon to evaporate.

I asked Josh's teachers and therapists how he could communicate like this. "He can talk," I said, "but he cannot read, write or spell." They said they could not explain it, but that FC was a miraculous new "thing" that unlocked hidden intelligence.

Although we were doubtful, we trusted these professionals. And we wanted to believe our son was intelligent enough to have taught himself to read, write and spell. We went along with their recommendation that Josh should continue using FC.

As months passed, it continued to be facilitated that Josh was being abused, was not protected by his family, or wanted to leave home to be safe. At one point, the police were called in to investigate claims he was making "plots and ploys to murder" his family.

I allowed the police to question Josh because they agreed to provide me with a videotape of the interview. It was heartrending to watch 43 minutes of Josh struggling with the facilitator, using spoken language to repeatedly say, "Can I stop now? Can I go back to the room? No, no, no! I don't want to do this." He repeatedly yanked his hand away from hers, turned the typewriter off and looked around the room while she "facilitated," concentrating intently on the keyboard. When an officer suggested that our son might want to stop, the facilitator repeated the FC lore—what he says isn't valid; just pay attention to what is typed. The investigation continued.

A few weeks later, Josh's grandfather was accused of sexual abuse. My involvement was implied by a facilitated statement about "the ploy by my mother to appear normal."

We were distraught. If our son had been abused by anyone, we certainly wanted to know, but none of this made sense. Josh had never spoken about anything remotely resembling sexual molestation. Yet his teacher claimed this communication was coming from him.

A final "facilitated" police interview resulted in a typed sheet describing specific graphic sex acts involving me. I was hysterical after reading the accusations. School personnel then said they were convinced that, although these were his words, Josh was lying. The detective in charge decided not to file any charges.

Josh Johnson and his sister, Samantha.

Despite that decision, I cried for weeks. I was terrified my child would be taken away from me, or that I might be arrested or forced to leave my home. I couldn't understand how the sweet, funny, talkative child I loved could have done this. Or why.

Then I discovered he didn't do it. We experimented with our own electric typewriter. I had believed Josh's hand could not be pushed to keys he didn't want to press, but I soon discovered that, holding his hand, I could spell whatever I wanted. If I looked away from the keyboard, the words turned to gibberish.

At our insistence, the school stopped using FC with Josh. His recovery from FC began the day he entered a new classroom. After months of having his spoken language ignored, he was finally being valued for himself again.

Some people call FC an inexpensive intervention. In fact, FC has enormous costs. We spent our life savings defending ourselves against false accusations. And we're not the only victims. FC has destroyed families, cost jobs, placed children and adults in homes with strangers ill-equipped to handle their needs, and undermined the credibility of professionals—who, despite the best of intentions—insist on ignoring the results of objective, scientific research.

—Cecilia Johnson
Georgia

Johnson, along with other parents, has formed a support group for families who feel they have been hurt by FC. The group provides information, copies of scientific research, articles, and videos examining FC. For more information, call (404) 973-4045.

This piece was adapted from THE IARET NEWSLETTER (Summer/Fall 1994). For more information, see "From Someone Who's Been There and Back," page 51.

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COMMUNICATION

continued from page 40

teacher is a piece of cardboard with the letters of the alphabet written on it. The teacher holds her hand gently around the child's hand; together they point to letters while the teacher says the letters and words aloud—"I... W-A-N-T... want... I want... S-T-R-A-W-B-E-R-R-Y... I-C-E-C-R-E-A-M... I want strawberry ice cream."

"Oh, you'll get it at lunch!" the teacher answers.

This technique of hand-over-hand spelling out of words is called facilitated communication (FC).

Australian educator Rosemary Crossley developed FC to help a woman with cerebral palsy communicate. Crossley began by using a hand-over-hand approach to help the woman, who had severe motor problems, indicate preferences by pointing to pictures. Crossley later expanded this technique to include the use of an alphabet board.

A few years later, Crossley began using FC with other students, including children and adults with autism and/or mental retardation. Although many of these individuals had not shown any previous evidence of verbal skills or literacy, through FC, they were reported to produce highly sophisicated communication.

In 1990, Douglas Bikden, a professor at Syracuse University in Syracuse, New York, observed Crossley and her students in Australia. He began writing about FC and teaching its use in this country.

Why is FC controversial?

The controversy surrounding FC has to do with authorship of the

Speaking with Kimberly

When I began facilitating with my daughter, Kimberly, I would sometimes ask myself if she was really typing these words, or was I somehow moving her hand. To suddenly have one's daughter type long sentences when she rarely spoke one word, is an indescribable feeling. Was this the same seven-year-old child I thought only understood at the level of a three-year-old?

Yet, I knew in my heart these were her hand movements and not mine. Because of my own doubts, however, I understood when I heard "through the grapevine" that some professionals who had already worked with Kim thought I was the one doing the typing. But I had no reason to lie, and it hurt to hear that people thought I was making this up. It might have been a little easier had they expressed their disbelief directly to me—though not in front of Kimberly.

Now, more than three years later, I have no doubt that all the amazing things Kimberly types are her own words, and at least one of the original doubters has become a staunch supporter of Kimberly's abilities.

None of our friends ever thought we were lying about Kimberly's abilities. They trust me, and they know that as a mother of five children, I don't have time to go around pretending my daughter types. They know that I facilitate with Kimberly because she has something to say. Also, some of our friends now facili-

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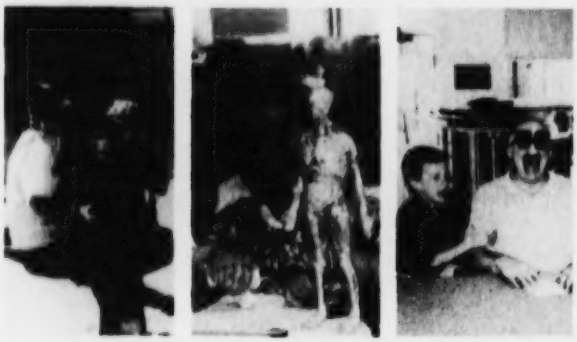

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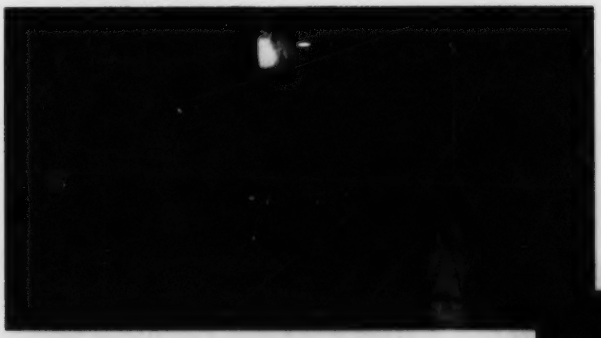


Marilyn Dixon began facilitating with her daughter, Kimberly, now 10, three years ago.

tate with her as well, so they know from personal experience that these are her words.

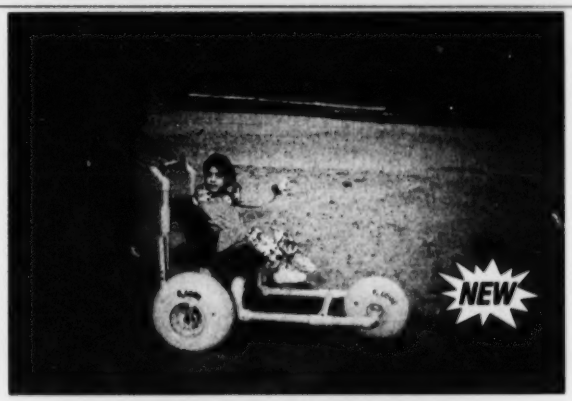
However, we still encounter professionals who doubt FC. About a year after she began using FC, Kimberly and I went to a conference where a speaker—an "expert" in the field of autism—spoke negatively about FC, even though he'd had no personal experience using the technique.

Since this speaker has never tried FC, his suspicions are understandable. However, it was not right for him to publicly criticize something he knows so little about, especially in front of an audience including many people whose children use FC.

Another time, we took our daughter to a neurologist because of her seizures. After being given a drug so she would fall asleep for an EEG, Kimberly, by facilitating with me, tried to tell the doctor how the drug made her feel. The neurologist immediately said, "Mom, what are you doing? She isn't even looking at that thing [her Canon communicator]." Although this person had never met Kimberly before that day, he was questioning her ability to communicate. It made me feel like he thought I was ignorant and that my daughter was not intelligent. The worse part was that he said this in front of Kimberly.

Professionals would do better to assume that all non-verbal or low-verbal individuals they encounter actually understand everything that is said. Even if these individuals are genuinely retarded, it certainly can't hurt to treat them as if they are not. And if they are intelligent and the "professional" treats them otherwise, it can damage their self-esteem. I believe many professionals reject FC because it would force them to admit they had been wrong about everything they have been taught or believed about the intelligence of those who cannot speak.

—Marilyn Dixon
Texas



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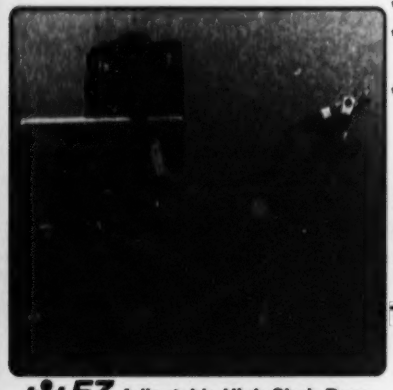

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spelled-out sentences. Critics believe the facilitator determines the letters to which the nonverbal individual points. In fact, many studies have shown that the pointing was controlled by the facilitator. In virtually all, the facilitators were unaware of their influence, and were shocked and dismayed by the results.

One of the most powerful of these studies was conducted in 1992 at the O.D. Heck Developmental Center in Schenectady, New York. Douglas Wheeler and his colleagues intended for their study to prove to skeptics that FC was a valid form of communication for the individuals with autism in this program. The three-month study included hundreds of trials involving 12 individuals with autism and nine facilitators. The results were completely unexpected. Not only was there not one, single correct response, the incorrect responses showed overwhelming evidence of facilitator influence.

Defenders of FC argue that studies such as this one have been done in artificial circumstances, and, therefore, are not valid. However, no studies published in peer-reviewed journals have offered support for FC.

How could a facilitator make someone point to certain letters without being aware of it?

It is very possible to gently guide someone's hand to point to certain letters without being aware you are controlling their movements. This is like an imperceptible nudge made to a car's

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Facilitating Love

There have been times in the past that family and friends have denied that my seven-year-old son, Joshua, was really "talking" to us. They have accused us of putting ideas in his mind, of spelling what we want to hear and just making up the things that Joshua has told us. Regardless of what they say, or what the "experts" have said, I know that FC works for my son.

I remember the first day we learned Joshua could use FC—we were thrilled. Imagine being able to hold a two-way conversation with your child for the first time. Thank God someone came up with this form of communication, which has unlocked so many sealed doors for us.

Now, Joshua can tell me what he wants, how he feels and what he wants to do. But most of all, he says that he loves me. And this is something I will not let anyone take from me.

If you have not tried FC, or are skeptical about it, why not listen to your heart and give it a try with your child? Unless you find a speech therapist who is willing to try anything to help your child, you will find the going rough. But I encourage you to stick with it. If your child is able to use FC, you will certainly be rewarded.

—Lewis Johnson
Virginia

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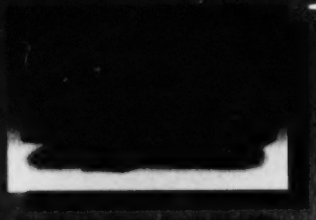

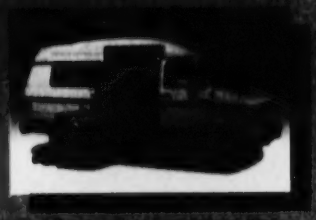

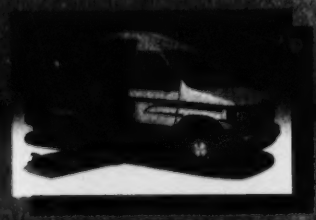

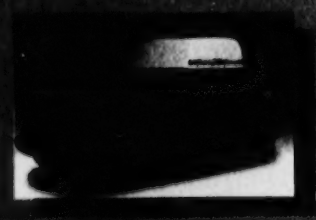

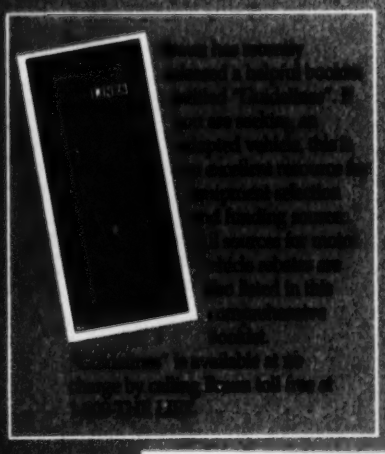

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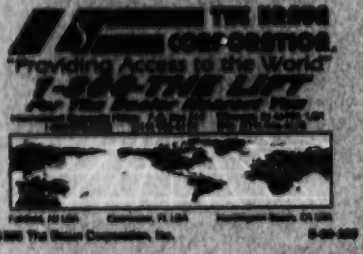

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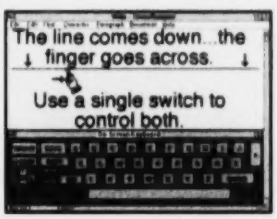

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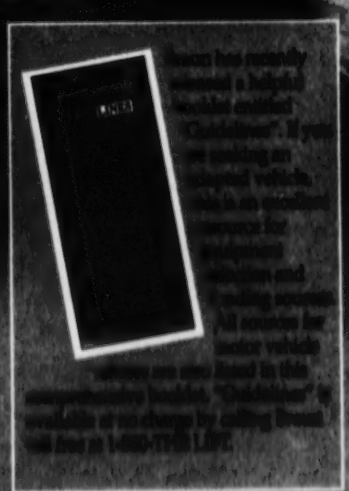

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Mostly For Parents

Books and Videos About Living With Seizures

Children with Epilepsy: A Parents Guide

Edited by Helen Reisner
Woodbine House, Inc., 1988

Edited by the mother of a child with epilepsy, this book is designed to help parents understand the nature of epilepsy in children and to familiarize them with therapy, coping skills and some of the special issues that arise when a child has severe seizures. Contributors to the book include parents and professionals.

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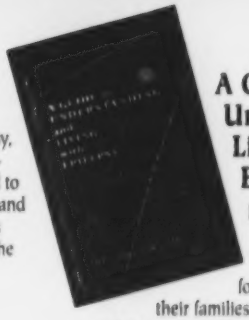

A Guide to Understanding and Living with Epilepsy

By Orrin Devinsky, MD
F.A. Davis Company, 1994

Easy-to-understand resource for people with epilepsy and their families. Covers a wide range of medical, social and legal issues. Topics include explanation of seizures and epilepsy; information about medication, side effects and risks; and getting the best medical care.

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Does Your Child Have Epilepsy?

By James E. Jan, MD, FRCP, Robert G. Ziegler, MD and Giuseppe Erba, MD University Park Press, 1983

Establishes "Ten Basic Rules" for parents of children with epilepsy. It addresses the initial fears parents have: Is my child going to die? Will he be retarded? How did he get epilepsy? Is epilepsy inherited? Provides information on how to manage your child's condition, how to work with physicians to obtain appropriate medical care and how to cope with changes that occur as both the child and family mature.

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Provides an explanation of seizure disorders in everyday language. Dispels many misconceptions about epilepsy with medically accurate information; describes what happens in the brain during a seizure, and explains why different people experience different symptoms.

Actual seizure footage is used. Doctors explain how they use family and patient histories , EEG's and other tests to look for causes and accurately diagnose epilepsy. A Family Video Library presentation. (1990)

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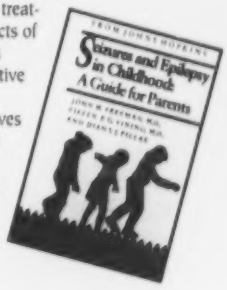
Seizures & Epilepsy in Childhood: A Guide for Parents

By John M. Freeman, MD, Eileen P.G. Vining, MD, and Diana J. Pillas
The Johns Hopkins University Press, 1990

Written for parents who want to understand as much as possible about the causes, mechanisms, treatment and social aspects of epilepsy. Encourages parents to become active partners in their children's care and gives them the background information (and vocabulary) to do so.



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continued from page 44

steering wheel as the driver thinks about making a turn.

It is natural for a facilitator to anticipate the next letter of a word—looking toward a likely letter and, without realizing it, subtly guiding the person's hand to that letter.

Does it really matter who controlls the pointing? If everyone believes the communication is coming from the child, and the child is doing so well, why does it matter?

Parents and teachers report that some children show improved behavior after FC is introduced. This may be due to the fact that when FC is used, other good things happen at the same time—the child gets a lot of positive, individual attention and close physical contact; he is often given more opportunity to express preferences, included in a greater variety of activities and treated with more respect. All of these good things can cause the child's behavior to improve, even if he or she isn't actually using FC to communicate.

If using FC only caused positive changes in the lives of children and their families, perhaps it would not matter who was controlling the pointing. But FC also poses serious risks:

• *Non-preferred life changes.* A facilitator may report that the child types requests that may not reflect the child's true desires. While misrepresentation of preferences regarding clothing or hairstyle may be harmless, FC messages have also led to changes in children's medical treatment and educational placement.

• *False allegations of abuse.* Even more serious is the fact that FC has resulted in a large number of sexual abuse allegations. When these communications are not coming from the child, and the allegations are false, the consequences can be tragic. In some cases, children have been removed from their homes. When these cases were investigated, it turned out that there was no abuse, and that the FC messages came from the facilitator.

• *Elimination of effective communication methods.* When a child begins using FC, his or her other forms of communication—gestures, signs or augmentative communication systems—are sometimes ignored. But if FC is not really the child's communications, these other forms of communication are vital for the child to be understood and to express his or her own, unique personality.

What is needed for someone to be able to communicate?

Communication is a very complex process involving a variety of intellectual, social, emotional and physical abilities. This process can pose challenges for many people with disabilities. For example, consider some steps a child might go through to obtain ice cream.

Step 1: The child must be able to think about eating ice cream; he must be able to imagine eating ice cream, even though he cannot see the ice cream. Imagining something one cannot see requires a certain level of intellectual sophistication.

Step 2: The child must understand that telling someone he wants ice cream will help him get ice cream! Understanding the necessity of directing communication to another person requires social understanding.

Step 3: The child must have a way to indicate what he wants—spoken words, sign language, written language, pictures, gestures or a specific behavior that those around him understand to mean "I want ice cream."

Communication can break down at any step. It is very important to find out where the problem occurs so we can add support to that part of the process.

For example, communication is affected when a child's thinking process is limited to what he or she can see (Step 1). In such cases, children can indicate preferences by being offered frequent, specific choices, such as a choice between ice cream and cookies.

For children with autism, a disorder affecting social interaction, communication often breaks down at Step 2. For example, a child may be aware that he wants ice cream (Step 1); he may even be able to say the words "I want ice cream" (Step 3); but he may not yet understand that he must direct that phrase to another person (Step 2).

Many children with autism develop unique ways of communicating that are easily understood by those who know them well. For example, one child with autism may recite a line from a television commercial for ice cream. Another may take someone's hand, lead that person to the refrigerator and look up at the freezer door. If a child's family, teachers and friends understand his or her individual ways of communicating, the child can communicate needs and desires. However, it is also important to try to teach more standard modes of communication.

Children with significant motor problems

continued on page 51

Position Statements on Facilitated Communication

A number of national professional groups and advocacy organizations have issued position statements on the use of facilitated communication (FC). Excerpts from these statements are reprinted below: [EDITOR'S NOTE: The Autism Society of America (ASA) has deliberated this issue over the last two years but has no plans to issue a position statement of FC. ASA stresses the importance of parents and professionals being fully informed about the pros and cons of the technique.]

"...Studies have repeatedly demonstrated that FC is not a scientifically valid technique for individuals with autism or mental retardation. In particular, information obtained via FC should not be used to confirm or deny allegations of abuse or to make diagnostic or treatment decisions."

—American Academy of Child & Adolescent Psychiatry, October 1993
(This position statement has also been endorsed by the American Academy of Pediatrics.)

"...A substantial number of objective clinical evaluations and well-controlled studies indicate that FC has not been shown to result in valid messages from the person being facilitated.

"...The Board of Directors of the American Association on Mental Retardation (AAMR) does not support the use of this technique as the basis for making any important decisions relevant to the individual being facilitated without clear, objective evidence as to the authorship of such messages. The AAMR strongly encourages the use and further development of valid augmentative and alternative communication techniques and approaches."

—American Association on Mental Retardation, June 1994

"...[S]pecific activities constitute immediate threats to the individual civil and human rights of the person with autism or severe mental retardation. These include use of FC as a basis for:
a) actions related to nonverbal accusations of abuse and mistreatment...;
b) actions related to nonverbal communications of personal preference, self-reports about health, test and classroom performance and family relations;
c) client response in psychological assessment...; and
d) client-therapist communication in

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INFORMATION THAT MATTERS, FROM PEOPLE WHO CARE

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may not be able to physically form words, causing a breakdown at Step 3. For example, such a child may know he wants ice cream (Step 1), and know he needs to tell someone (Step 2), but he may not be able to make his mouth form the word in an understandable way (Step 3). Providing this child with augmentative methods of communicating—signs, gestures, a picture board or an alphabet board connected to a speech synthesizer—will allow him to communicate successfully.

An alphabet board or keyboard, as used in

From Someone Who's Been There and Back

I was the facilitator for a child with autism who, through facilitated communication (FC), made allegations of abuse against members of her family. I continue to struggle to understand how the use of this seemingly harmless technique could have caused so much pain to so many people.

I was introduced to FC by staff members in my school system. I had worked for five months with this particular child using traditional techniques, but I'd had little success obtaining reliable, verbal communication. Other staff members introduced the child to FC. After a few months, they reported an emergence of words.

By fall, the child was producing occasional sentences. At that time, I became her primary speech/language therapist and began to work more closely with her. Under the supervision of the other facilitators, I learned the technique.

The child resisted at first, but gradually began extending her hand to me when I sat beside her with the board. In structured, language-based activities, she began to respond in words, then phrases and, finally, sentences.

As her ability to use FC increased, the other two facilitators began to report "communications" from this child indicating anger and a desire to kill herself. Her "team" (composed of parents, teachers, administrators and special education staff) agreed that these feelings could be considered "normal" for someone who was able to communicate for the first time. No one questioned the validity of the communications.

By mid-winter, the other facilitators and I were using FC to have "spontaneous" conversations with this child. These conversations seemed to be student-initiated. Her "communications" often centered on feelings of anger and frustration. Eventually, she alleged that she was being hit by family members.

We agreed not to report our "findings" until we were sure of what we had. We continued documenting the conversations and watching for behavioral or physical changes. I feared for the child's safety and speculated on the conditions of her life at home.

Shortly thereafter, during a "spontaneous" conversation this child "stated" she was being abused by her father. The description was specific enough to warrant concern. We reported the findings to the Department of Human Services (DHS). During the three-hour interview with DHS, this child, through FC, graphically described events of sexual abuse. DHS authorities removed her and a sibling from their home.

DHS appointed a guardian ad litem (a lawyer hired by the state to protect the rights of the child) who arranged testing to find out if the communications were coming from this child.

In the meantime, I attended an FC workshop at a local university. As the workshop leader reviewed a "checklist" for facilitating correctly, I realized the child I was working with did not always look at the board. Although the workshop leader pronounced my technique "exactly right," I was concerned. I asked the leader and other "experts" if they had ever worked with students who did not look at the board. They all said they had, and that they believed their clients had memorized the board's layout.

I came away from that workshop even more convinced that FC worked. The workshop leaders acknowledged negative validation studies, but said those studies were flawed.

On the day of the child's FC test, I felt nervous, but confident the results would support the validity of her communication. This test included picture identification, story comprehension, hands-on activities and short-answer questions that she should have easily known. The child seemed to enjoy the activities, and I felt she was communicating in her usual way.

The results devastated me. Not one of her answers was correct. In fact, the picture-identification section clearly showed that "her" answers described the objects I had seen. The abuse charges were dropped.

A few weeks after the testing, I read those negative studies. I could no longer ignore the fact that the communications were coming from facilitators and not the clients. I convinced my employer to stop using FC.

Still, I carried guilt and shame for my role in bringing charges against this child's family. I knew I could not heal from the experience unless I apologized. A year later, I sat down and talked with the family. Although they were extremely hurt by the experience, her father told me they understood how I became involved. They had also wanted to believe in FC.

—Janyce L. Boynton
Maine

This piece was adapted from The IARET Newsletter (Summer/Fall 1994), published by the International Association for the Right to Effective Treatment (IARET). IARET (763 Main St., #10, Waltham, MA 02154-0604, 617/891-7554/voice and fax) is an educational and advocacy group helping to ensure that all individuals with disabilities "benefit from the most progressive, effective interventions possible." Annual newsletter subscription is $9 for three issues.

Position Statements on Facilitated Communication

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counseling or psychotherapy…

"…[F]acilitated communication is a controversial and unproved communicative procedure with no scientifically demonstrated support for its efficacy."

—American Psychiatric Association, August 1994

"…When information available to facilitators is controlled and objective evaluation methods are used, peer reviewed studies and clinical assessments find no conclusive evidence that facilitated messages can be reliably attributed to people with disabilities… Moreover, FC may have negative consequences if it precludes the use of effective and appropriate treatment, supplants other forms of communication, and/or leads to false or unsubstantiated allegations of abuse or mistreatment.

"…Information obtained through or based on facilitated communication should not form the sole basis for making any diagnostic or treatment decisions.

"ASHA strongly supports continued research and clinical efforts to develop scientifically valid methods for developing or enhancing the independent communication and literacy skills of people with disabilities…"

—American Speech-Language-Hearing Association (ASHA), October 1994

"TASH regards access to alternative means of expression [as] an individual right.

"TASH encourages its membership to become informed about the complexities of FC training and practice and to stay informed of new research… TASH encourages people who decide to become facilitators to seek training… TASH encourages careful, reflective use of FC. TASH encourages facilitators to work in collaboration with individuals with severe disabilities to find ways of confirming communication competence when using facilitation…

"TASH urges that when allegations of abuse or other sensitive communication occur, facilitators and others seek clarification of the communication and work to ensure that users of facilitation are given the same access to legal and other systems that are available to persons without disabilities. It is important not to silence those who could prove their communication competence while using facilitation or any other method of expression…"

—TASH (The Association for Persons with Severe Handicaps), October 1992

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COMMUNICATION

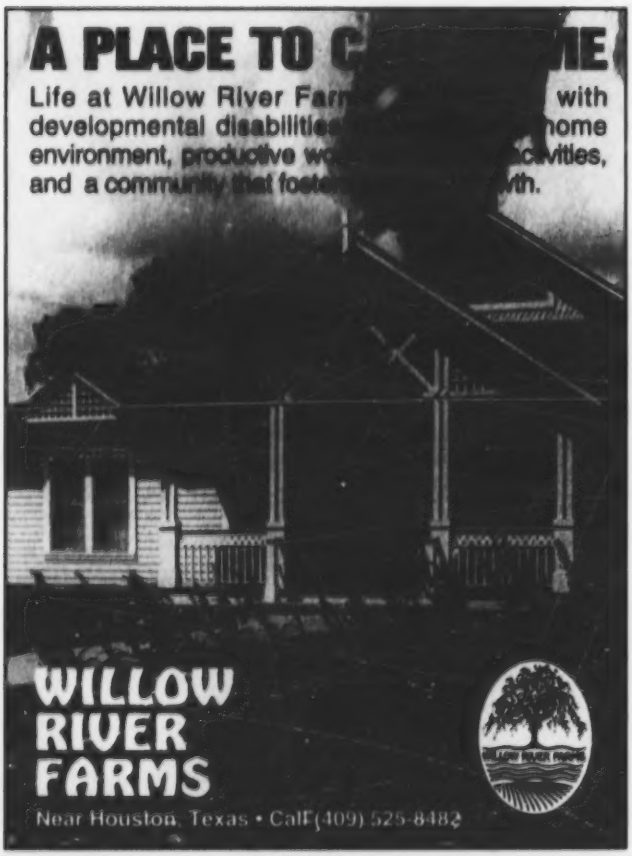
FC, can only address communication problems that occur at Step 3. It cannot fix problems at Step 1—the "thinking" part of the process, nor can it fix problems understanding the social use of communication (Step 2).

And FC can only help with problems at Step 3 if the child is able to spell words and sentences, but is not able to point or indicate letter choices independently. However, any child with the ability to spell and write sentences, and the motor ability to guide an adult's hand to specific letters, has the potential to develop *independent* communication skills through augmentative communication. A child who does not have the thinking skills to write and spell, or the necessary social understanding for complex communication, would not be able to use FC, but may benefit from some form of augmentative communication.

At school they are using FC with my child. What should I do?

If your child's teachers, speech therapists or other professionals are using or suggesting the use of FC, we suggest the following steps:

- Consider whether the sentences produced, and the spelling and grammar abilities, are consistent with your child's abilities as you and professionals know them.
- If you believe your child is communicating successfully with FC, he or she is an excellent candidate to be able to



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quickly learn to use an advanced augmentative communication system. Recommend that the child be evaluated for this type of communication aid.

- If FC is being used and you believe the communication is being controlled by the facilitator, it is important to meet with your child's team and discuss your concerns. The communication methods used at school must be consistent with your child's IEP. If FC is not in your child's IEP, you should not have difficulty eliminating its use. The team should work with you to explore other communication methods.
- Most importantly, to einsure that your child is working with the most optimal communication methods, a thorough evaluation of your child's cognitive, social, motor and communication abilities can help the team understand and address any problems interfering with his or her ability to communicate. Such an evaluation can be done through the school, however, if there is disagreement about an optimal communication approach, you have the right to an independent evaluation paid for by the school once they have done their own evaluation. An independent evaluation can provide objective input regarding optimal communication approaches. **EP**

Karen Levine, Ph.D., is director of psychology at the University-Affiliated Program, Institute for Community Inclusion, Children's Hospital, Boston, Massachusetts. She is also an instructor at Harvard Medical School. Karen specializes in psychological consultation for children with autism, Williams syndrome and other developmental disabilities, and their families.

Robert Wharton, M.D., is chief of developmental pediatrics and rehabilitation at Spaulding Rehabilitation Hospital and chief of pediatric rehabilitation at Harvard Medical School. Dr. Wharton specializes in medical care and behavioral consultation for infants and children with complex medical problems, injuries and/or developmental disabilities.

To learn more about FC...

- **Facilitated Communication: The Clinical and Social Phenomenon,** published in 1994 and edited by Howard C. Shane, Ph.D. of Children's Hospital in Boston, provides an up-to-date look at the what is currently known about FC. Topics include history, legal issues, research methodology and research results. Available from Exceptional Parent Library (800/535-1910); $45.

- **The American Speech-Language-Hearing Association (ASHA)** has issued a technical report on FC. The report was developed by a committee, which included both professionals and parents. The 47-page report, released in October 1994, provides a detailed overview of FC, with an appendix summarizing the methodology and results of every published research study on the subject. Also included is a four-page minority statement issued by two committee members who disagree with some conclusions of the technical report. These materials may be obtained by sending a self-addressed 12 x 9-inch envelope stamped with $1.93 in postage to ASHA, Information Resource Center, 10801 Rockville Pike, Rockville, MD 20852; (800) 638-8255 (V/TTY), (301) 897-7348 (fax).

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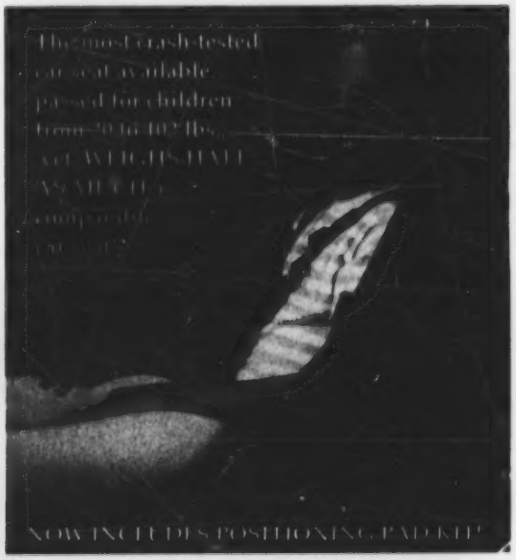

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431

Using the Telephone

by Susan Phillips

Tasha is all smiles as she talks to her mom on the telephone using a special amplifier attached to the earpiece.

We have all heard stories of the three-year-old who dialed 9-1-1 and saved his parent's or sibling's life. Learning to use the telephone is not only fun for children, but an important daily living skill as well.

These days, the telephone is used for everything from shopping to banking. However, a child with a hearing impairment or an inability to speak clearly may not be able to use the standard telephone.

Modifications

Fortunately, many relatively simple modifications can enable children with hearing impairments to use the telephone. For instance, a child with a mild or moderate hearing loss may be able to use a standard telephone with an amplified handset and volume control. When purchasing these handsets, bring the telephone to the dealer to match the color and brand. Slip-on amplifiers, which fit over the earpiece of the receiver, can be purchased from Radio Shack for as little as $20.

Another option is to buy a behind-the-ear hearing aid that includes a telecoil with a switch that lets the aid receive sound directly from the telephone rather than from the aid's external microphone. This option has the added benefit of tuning out environmental sounds or background noise.

For children with more severe or profound hearing losses, or those who cannot communicate well through speech, a teletypewriter—commonly called a TTY—may be the answer.

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Other names for TTY are "TDD," which stands for "telecommunications devices for the deaf," or, less common, "TT," which stands for "text telephone."

TTYs include a typewriter-like keyboard and view screen. The handset of a standard telephone fits into rubber cups on a cradle, which is built into the TTY. (In older TTY models, this modem-like device is an attached appliance called a "coupler.") A monitor light on the TTY (or, in older models, its coupler) indicates the status of the outgoing call—a steady light indicates a dial tone; the light flashes to indicate rings or a busy signal. The TTY user types outgoing messages on the keyboard and reads incoming messages as they appear on the view screen. Since a TTY is used with a standard phone, any special features on your own telephone, such as rapid dial, are also available for the TTY.

TTY prices range from $280–$500, depending on optional features such as built-in answering machines, printers and additional memory to store messages. Some TTYs plug right into a phone outlet and have a dial function,

Portable fold-up TTYs are becoming increasingly available. Photo courtesy of Ultratec, Madison, WI.

eliminating the need for a telephone. TTY modems, which allow one to use a computer as a TTY, are also available. These modems typically cost about $300.

TTY relay services—available in every state and through major long-distance carriers—act as intermediaries between TTY users and users of standard telephones. A deaf child who uses a TTY could use a relay service to call her grandmother, who may not own a TTY.

"Voice carryover" (VCO) is an option built into some TTY models, or available through most relay systems. With VCO, a person can speak into the receiver while receiving typewritten messages from the other person, or listen to incoming messages while typing outgoing messages. This allows someone who

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Circle #185

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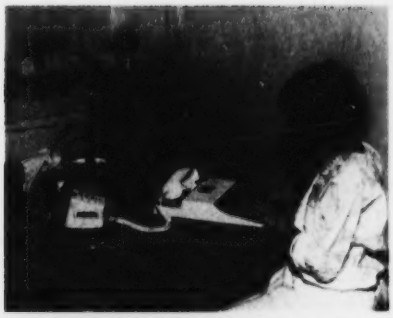

Making a call using a Memory Printer TTY, Model MP2000, made by International KROWN Technologies, Inglewood, CA.

can speak but not hear, or someone who can hear but not speak, to make more efficient use of time on the telephone. To set up your home phone system to use VCO through a relay service, you need only a "double modular jack" (about $5, available at Radio Shack), which allows the TTY and the telephone to be hooked into the same phone line.

To alert someone with a hearing impairment to a telephone call, devices such as flashing light systems are available. In addition, personal vibrating devices work like beepers and can include lights of different colors to indicate whether an incoming signal is coming from the telephone, the doorbell or the smoke alarm.

Special telephone access systems are available for children with hearing impairments, motor difficulties or both. These include voice-activated phones or remote-control speaker phones that can be activated by a switch mechanism.

Special services

Currently, about 33 states have adaptive telecommunications equipment distribution programs, which distribute free or reduced-cost telephone equipment to children and adults with disabilities. In addition, many major long distance phone companies—including AT&T, MCI and Sprint—provide relay services and may also offer additional benefits, such as discounts on long distance calls for homes with TTY machines. For more information on state programs, long distance services and other information about TTYs (including local resources), contact Telecommunications for the Deaf, Inc. (TDI), 8719 Colesville Rd., Ste. 300, Silver Spring, MD 20910, (301) 589-3786, (301) 589-3006 (TTY), (301) 589-3797 (fax). **EP**

Susan Phillips, M.Ed., CCC-A, is an audiologist at the Kennedy Krieger Institute in Baltimore, Maryland. She has a master's degree in deaf education and is a doctoral candidate at the University of Maryland. Her grandparents are deaf.

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Circle # 45

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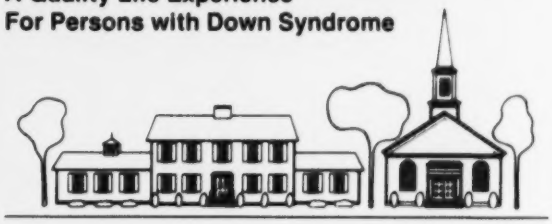

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Circle #204

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Circle #78

by Richard Epstein

Long-term Physical Therapy; Wheelchair Ramps

Q Our health insurance will not pay for long-term physical therapy for our child unless he shows "measurable progress." The therapist says that without long-term physical therapy, my child will develop secondary medical problems, such as contractures, which will be costly in the future.

A Insurance policies generally cover treatments that are related to existing medical conditions or illnesses. They don't usually cover preventive care.

Although insurance companies may cover the treatment of a contracture (when a joint loses normal movement and becomes static), they will not usually cover physical therapy designed to prevent contractures, or to maintain a particular range of joint motion.

Development of health insurance

When health insurance was developed in the United States, preventive care, doctor visits and medical tests were relatively inexpensive. Thus, health insurance was originally designed to cover the more expensive hospitalization and surgery.

As doctor visits and medical tests became more expensive, they were added to the list of covered items. The guiding principle, however, seems to have been to provide coverage for treatment for medical conditions or illnesses, not for prevention. However, in the past few years, some new insurance programs have begun to cover some types of preventive care.

These days, the fact that a patient is making progress in physical therapy may be viewed as evidence that the therapy involves treatment, rather than prevention or maintenance. In your son's case, progress may be defined as a positive change in the range of motion of a particular joint, or an improvement in the child's ability to move more easily in specific situations.

If this type of progress is occurring and continues, and the insurance company does not pay the claim, file an appeal. Write "Claim Appeal" on the envelope and on the letter asking the company to re-evaluate its decision. Include letters from your child's doctor and therapist describing the therapy's purpose and documenting any progress that has been made.

If no progress appears to be occurring , I don't think your insurance company is likely to cover the therapy. However, if your child is in school, and the contractures interfere with educational activities, the school may agree to pay for physical therapy that takes place at the school. It's important to include the therapy on your child's Individualized Education

In my March column ("A New Insurance Plan for Individuals Considered 'High Risk'"), I discussed a new health insurance program, offered by the Arc, designed to meet the insurance needs of children and adults with disabilities.

Although the Arc originally planned to offer the insurance program nationwide, it apparently cannot yet be offered to residents of New Jersey, Connecticut, Vermont or New Hampshire because of certain state insurance regulations. The Arc is working to solve this problem.

—R.E.

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Plan (IEP) because school districts are legally obligated to provide all services listed on the IEP.

Q My insurance will pay for my child's wheelchair, but the policy will not pay to install a ramp on our home. That means we have to lift our child, and his wheelchair, to get him in and out of the house. We would like him to be able to go outside independently.

A Health insurance is designed to pay for medical equipment, and not for non-medical equipment or architectural modifications. However, trying to predict what will be considered "medical equipment," and what will not, can sometimes be difficult.

An electric wheelchair, for example, is considered "medical equipment." Insurance policies will generally cover an electric wheelchair, as long as it meets the requirements to be classified as a "medical necessity." However, a wheelchair ramp (and lift, too) will not usually be covered because it is considered "non-medical."

Finding help

Insurance is not the only source of help in trying to build a wheelchair ramp. Many volunteer organizations may build a ramp for free. The Telephone Pioneers of America, a group of volunteers from AT&T, Canadian phone companies and local phone companies, may build a ramp, or do other architectural or engineering projects for you.

Local chapters offer different services. For your nearest chapter, contact Telephone Pioneers of America, 930 15th St., Denver, CO 80202.

Your local independent living center may have information about other groups that may help build or provide funding for your ramp. Local Parent Training and Information Centers (PTIs) may have similar information. (A directory of PTIs can be found in the *1995 Exceptional Parent Resource Guide.*) State agencies, such as divisions of vocational rehabilitation services, health departments and developmental disabilities agencies, may also provide some funding or advise you of other possible funding sources. **EP**

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, *209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).*

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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Circle # 17

WHAT'S HAPPENING

Publications

• *Guidelines: Choosing the Right Mobility Equipment* is a primer for people with disabilities who are looking for their first adapted van. This free booklet discusses considerations associated with being a passenger or driver, finding a vehicle to adapt, full-size vans versus minivans, lift options and finding help in paying for a van conversion. Contact the Braun Corporation, 1014 S. Monticello, P.O. Box 310, Winamac, IN 46996; (800) 843-5438, (219) 946-4670 (fax).

• *Educating Children with Tourette Syndrome* is a free 23-page in-depth guide. Topics include tics, associated disorders and behavioral features and learning disabilities. The guide has an extensive bibliography. Contact the Tourette Syndrome Association, 42-40 Bell Blvd., Bayside, NY 11361-2861; (800) 237-0717, (718) 279-9596 (fax).

• *IN Motion* is a new publication that offers information and guidance for people with limb disorders or amputations. Articles will address sports and recreation, physical therapy tips, new technology and product information. For a free copy, contact *IN Motion*, Amputee Coalition of America, 1932 Alcoa Hwy., Knoxville, TN 37920, (800) 355-8772.

• *Learning Together* is a free newsletter published twice a year (June and Dec.) to connect parents of children with autism or related disorders for "friendship, encouragement and information." Readers can list themselves in the newsletter if they want to find pen pals. For a copy, send a self-addressed stamped envelope to Annette Vander Weide, 149 E. Cortner St., Hanfrod, CA 93230. For a pen pal listing, include a paragraph describing yourself.

Videos

• *Parents Can Make a Difference* is a 90-minute, open-captioned video for parents of children who are deaf or hard of hearing. Topics include parent support, tips for parents in rural areas and the IEP process. The video features three parents sharing their experiences. Free to Minnesota parents; $10 for others. Send payment (payable to the Minnesota Foundation for Better Hearing and Speech) to the Parent Network, MFBHS, 166 4th St. East, Ste. 320, St. Paul, MN 55101; (612) 223-5130 (V/TTY).

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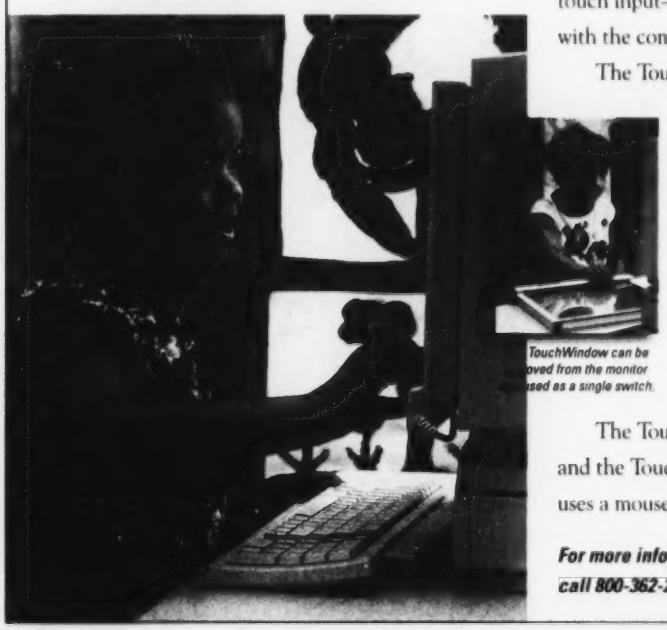

TouchWindow can be moved from the monitor and used as a single switch.

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The TouchWindow for the Macintosh works with all Macintosh software, and the TouchWindow for IBM/Compatibles works with most software that uses a mouse. Also available for the Apple II Series.

For more information or a free product catalog, call 800-362-2890.

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Circle #109

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1995 Special Olympics World Games

Special Olympics invites proud families, relatives and friends of its outstanding athletes to join in the fun and excitement at the 1995 Special Olympic World Games in New Haven, Connecticut, July 1–9. Athletic events will also take place in West Haven, Hamden, New London and Old Lyme, Connecticut.

Share the job of cheering 7,000 athletes representing 140 countries from around the world. Join thousands of other family members and friends who will gather to support these spirited athletes as they participate in the largest and most exciting sports event of 1995.

The 1995 Special Olympics World Games Family Services Committee will provide hospitality and information to the families of the athletes who will attend the games. Centrally-located family centers will provide a place for families to relax, meet others and have refreshments. A main family center will be located at the Yale Bowl; satellite centers can be found at other sports venues. The main center will feature entertainment, a children's play area and daily competition schedules. A siblings program for brothers and sisters of athletes, aged 8 and older, is also planned.

An extensive shuttle transportation system will be available to transport families between sports venues. It is also expected that transportation will be available from area hotels and towns.

For travel and car rental information, contact Adelman Travel, the World Games' official travel agency (800/666-8886). For information about New Haven area hotels, motels, bed and breakfast inns, call the Greater New Haven Convention and Visitor's Bureau (800/332-7829).

And be sure to stop by and visit with *Exceptional Parent!* You'll find our booth at the family center at the Yale Bowl.

Support Groups

• ***Twin-to-Twin Transfusion syndrome*** (TTTS) is a condition, which sometimes occurs in pregnancies involving identical twins or higher multiples, when blood passes disproportionately between one baby and another through connecting blood vessels in a shared placenta. Survivors of TTTS may be left with a number of serious disabilities, including cerebral palsy. The Twin-To-Twin Transfusion Syndrome Network (2592 W. 14th St., Cleveland, OH 44113; 216/731-6940; 216/585-2626, fax) provides support and information to families and medical professionals through meetings, participation in conferences and a quarterly newsletter.

• ***Myasthenia gravis*** is a chronic neuromuscular disease marked by weakness and muscle fatigue. The Myasthenia Gravis Foundation of America (222 S. Riverside Plaza, Ste. 1540, Chicago, IL 60606; 800/541-5454, voice; 312/258-0461, fax) is starting a pen pal network for parents of children with myasthenia gravis and for teenagers with the condition.

Autism Research

The National Alliance for Autism Research (NAAR) is a non-profit organization dedicated to funding and promoting biomedical research into the causes, prevention and treatment of autism and related developmental disorders. Run by parents, NAAR is the only organization in the U.S. dedicated solely to fundraising on behalf of increased medical research in autism. NAAR plans to award research grants, publish a newsletter, sponsor symposia for researchers and support the work of the brain bank at Massachusetts General Hospital, a major source of research on neurological studies. For more information, contact NAAR, Two Center Plaza, Ste. 420, Boston, MA 02109; (508) 470-4747, (908) 359-9957. NAAR's Internet address is naarlondon@delphi.com. **EP**

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Circle #139

It Takes Two To Talk

A Parent's Guide To Helping Children Communicate

by Ayala Manolson M.Sc., CCC

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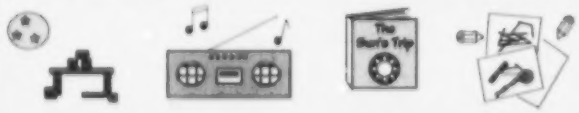

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May 1995

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If Yes, are you a: ☐ Physician ☐ RN ☐ Physical Therapist ☐ Occupational Therapist ☐ Speech Pathologist, Audiologist ☐ Other (please indicate) _____

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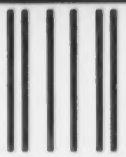

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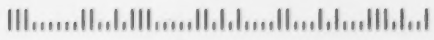

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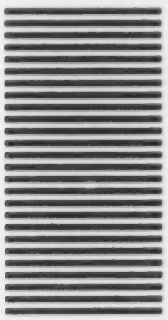

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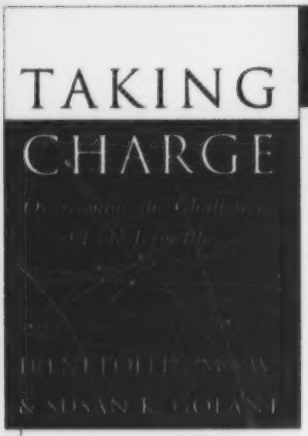

Magazine editors get many books from publishers, eager to have a current book receive a favorable review. In an effort to keep up with these, I often take a few along for on-airplane reading. I tend to be semi-conscious at such times, and many books serve as a sedative to help me sleep. Those were the circumstances under which I began reading TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS *by Irene Pollin, a psychiatric social worker. Very quickly, I was wide awake and excited. This was a terrific book! Although the book was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members.*

In fact, Irene Pollin is a parent as well as a psychiatric social worker. After the loss of two of her own children, she returned to school for training as a psychiatric social worker. After 20 years of research and work in family counseling, she developed "medical crisis counseling," a new model for working with individuals with chronic illnesses and their family members. This model of counseling is focused on the medical crisis, not on personal or family history.

In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope with long-term effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed. In addition to writing this outstanding book, Pollin established the Linda Pollin Foundation, named after her late daughter, which—in collaboration with Children's Hospital in Boston—provides this specific training to mental health and other health-care professionals. In Pollin's words—"I have discovered that by confronting and taking charge of your fears, you can learn to accept your [or your loved one's] long-term condition. Indeed, you can once again take charge of your life. This book will show you the way."

Thousand of parents and professionals first learned about EXCEPTIONAL PARENT *from nationally-syndicated columnist Ann Landers; here's what she says about* TAKING CHARGE: *"[This] book... should be required reading for everyone facing the challenge of long-term illness, whether their own or that of a loved one... It could be the most valuable gift you will ever give."*

Beginning with this issue, EXCEPTIONAL PARENT *presents a series of excerpts from* TAKING CHARGE.

—Stanley D. Klein, Ph.D.

TAKING CHARGE is available from Exceptional Parent Library (800/535-1910). The following is an excerpt:

Identify Your Problems

Knowledge is power. In order to handle the problems you're bound to encounter, you must first be aware of them. As painful as it may be, with awareness comes the possibility of adjustment, integration and resolution. Without it, you may become stuck, confused or embittered. With insight, however, you can anticipate the rough spots. Because you can expect certain challenges, you prepare for them and learn how to handle them, thus diminishing their effect on you.

To help visualize the complexity of problems inherent in coping with long-term illnesses, picture a pane of safety glass that has been hit very hard by a sharp object such as a small stone. The glass doesn't shatter and fall to the ground. Instead, immediately around the center of impact, a web of fine cracks appears. The network grows, radiating in every direction. Some fissures are short, others long. Some spread directly from the center while others intersect. All the fractures are connected, even those at the farthest edges of the pane, because they result from the same impact. Although the glass is more fragile than before it was hit, it still remains whole in its fractured state.

So it is with your long-term illness. You will encounter a myriad of intersecting medical, social, emotional and economic problems. There are the obvious physical disabilities to overcome: pain; restricted movement, activities or diet; dependency on medication and medical technology; to name a few. In addition, your relationship with family and friends may change. You'll confront the often intimidating medical profession. Your income and savings may diminish, possibly altering your social status. Your loved ones—the major source of emotional support—may feel as vulnerable and helpless as you.

Anyone who denies being overwhelmed at this time is simply not telling the truth. Yet, even as you consider the number of problems resulting from the impact of long-term illness on your life, you'll recognize that although weakened and perhaps impaired, you remain the same person. Like the pane of glass, you've been hard-hit but you are whole and you are capable of adjusting to the fate you have been dealt.

Consider making a flow chart or diagram showing (and concretizing) the intersection of the problems arising from your illness as the fissures in a cracked pane of glass. Put your illness in the middle and draw and label the issues you must deal with as lines radiating from the center or intersecting with one another. Then draw a circle around your design to show that wholeness still exists, despite the disease. This exercise can help you bring your own problems into focus, so you'll know what you're up against. **EP**

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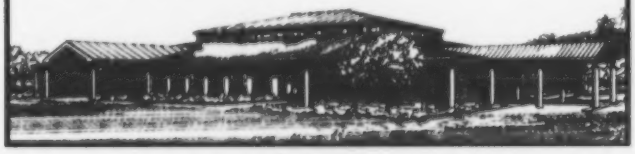

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Circle # 77

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ASK THE DOCTOR

by David Hirsch, M.D.

"Smart Drugs;" Undiagnosed

Q We have heard a lot about "smart drugs," especially for children with Down syndrome. Recently on the news show *Day One*, a drug called Piracetam was shown to help learning ability in a child with Down syndrome. Our son is six years old and has Down syndrome. We would be interested in anything that may help him reach his full potential. What do you think about the use of these new drugs?

A The use of the so-called "smart drugs"—as well as vitamin, mineral and amino acid supplements—is a very controversial area in the treatment of children with certain developmental disorders. Recently, there has been much publicity regarding "smart drugs," specifically Piracetam, as a supplement for children with Down syndrome. Piracetam, often used in conjunction with other supplements (typically vitamins, minerals, amino acids and, sometimes, digestive aids or enzymes), is one member of a new class of drugs that are thought to enhance learning and memory. No commonly accepted mechanism of action has been established; that is, if it works, we are not exactly sure how or why.

Piracetam (trade name Nootropil) is considered an orphan drug. An orphan drug is a drug still in clinical testing and not yet approved by the Food and Drug Administration (FDA), or a drug designated for use in rare disorders affecting 200,000 people or less. Piracetam's only indicated use is for a rare condition called myoclonus (a type of seizure disorder); its use is not indicated for learning disabilities, mental retardation or Down syndrome. In fact, at this time, I do not believe Piracetam can be legally imported into the U.S. Also, because of a lack of appropriate scientific research on the use of the drug in individuals with Down syndrome, the National Down Syndrome Society does not recommend the use of Piracetam for children with Down syndrome.

I wholeheartedly agree that any child—regardless of disability—should be allowed to reach his or her full potential. Certain less conventional therapies—such as drugs or other nutritional or vitamin supplements—may have a role if used in a cautious manner. And any such supplements should be used only in conjunction with more conventional medications, helpful therapies, an appropriate educational program, a nutritious diet and appropriate exercise.

If you wish to consider the use of any of these "smart drugs" or other supplements, I encourage you to check with your son's pediatrician to make sure no other medical, therapeutic or educational options need to be considered first. Your son's pediatrician can also assess the possibility of any drug interactions. Under *no* circumstances should one assume that if a certain amount of a vitamin or supplement has been shown to be helpful, then twice as much (or more) of that substance will be even better.

Q Our eight-year-old daughter has global developmental delays (fine and gross motor and cognitive delays). Over the years, we have taken her to many neurologists, specialists in developmental disabilities, occupational and physical therapists, psychologists and pediatricians. None of these specialist has been able to give us a definitive diagnosis for our daughter's problems. My wife and I are uncomfortable with this situation. We are also worried about any future children we may have. Can you think of anything else we might do?

A You have done a significant amount for your daughter already. Lack of a specific diagnosis is one of the most frustrating situations for patients, parents and physicians. Patients without a specific diagnosis often tend to be "placed" into broad descriptive-based categories that describe symptoms such as hypotonia (low muscle tone), developmental delay, non-specific learning disability, encephalopathy (a disease of the brain, either unchang-

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In this column, David Hirsch, M.D., a pediatrician and member of the EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch mentions specific products or medications only to illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-8742 (Fax).

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Circle # 167

continued from page 67

ing or progressive) or cerebral palsy (when used in its broadest sense to mean muscular impairment or poor coordination).

Such general classifications can make it difficult to design and obtain insurance coverage for appropriate therapies and treatments. It can also make it more difficult to qualify for certain state and federal health programs that allow coverage only for certain specific "diagnoses." And parents of a child without a diagnosis are less likely to find appropriate support groups or other resources.

Family and friends may be surprised that you have not found an "answer" to your daughter's problems. You are probably getting a number of unsolicited "answers" and opinions from well-meaning family members and friends.

If you have not already done so, you should consider a genetics consultation. This would include a detailed look at your family history, chromosome studies and an evaluation of your daughter's symptoms and appearance to see if they fit any particular syndrome. This type of consultation might also address your anxieties with regard to any future children.

Medical knowledge changes rapidly, so more information about your daughter's condition may become available in the next few years. In the meantime, even without a diagnosis, you need to continue to deal with your daughter's needs for occupational, speech and physical therapy, and to make sure she is in a school program that best meets her educational needs.

Over the years, I have seen many patients who were undiagnosed; some remain undiagnosed. But their parents, like you, have accepted these children just as they are. Parents have taught me that whether a child has a specific diagnosis or not, that is the most important thing you can do. **EP**

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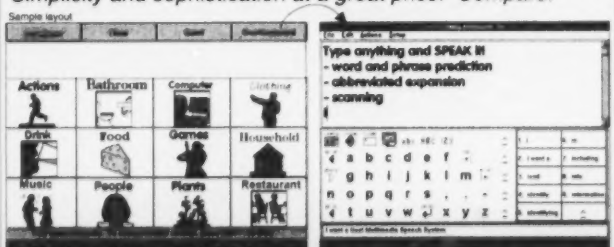

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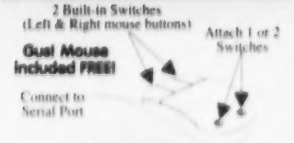

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For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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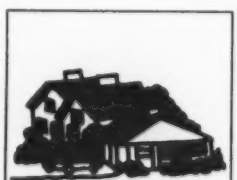

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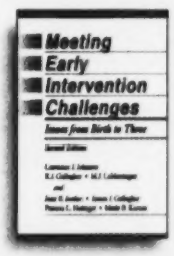

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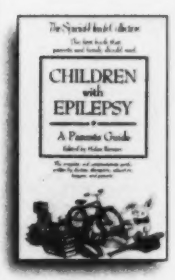

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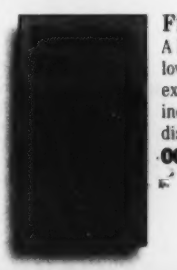

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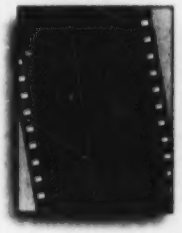

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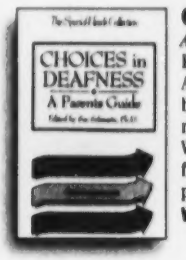

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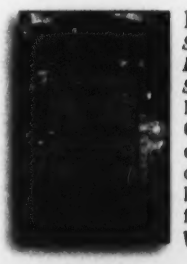

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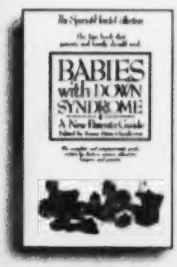

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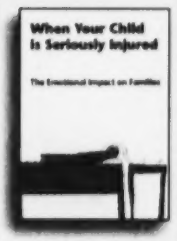

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During T-ball games, Preston signed across the field to Genelle since she couldn't hear the coach.

CHILDREN'S PAGE

SIGNING WITH MY SISTER

by Preston Timperlake

My sister, Genelle, is deaf. I communicate with her by using sign language and by talking. When her hearing aids are off, or if there is any noise, talking doesn't work, so I use sign language. Using sign language is lots of fun because you don't have to talk.

Genelle has deaf and hearing friends, and so do I. Daniel, my best friend, who lives in Virginia, has a sister, Kristie, who is also deaf. Sometimes, Genelle calls Kristie on the TTY. We all got together last year at the American Society for Deaf Children convention in Florida.

I have been teaching some signs to my kindergarten class. My friends enjoy communicating with the signs they have learned. When I sign with my hearing friends, they try to guess what I am saying. When they ask how I learned to sign, I say, "I learned it from my sister, Genelle. My sister is the only deaf person in my family. I can sign to her anytime I want."

Last year, Genelle and I played on the same T-ball team. Sometimes I signed to tell her what other people were saying. During the games we signed across the field because Genelle couldn't hear the coach. That made me feel happy because I was signing to Genelle, and she is one of my best friends.

My mom is president of the American Society for Deaf Children. She tells a lot of people how important it is to be able to communicate and to understand what people are talking about. All the people in our family can sign, even my little sister, Erin. She can sign "milk" and "Dad" and a few other words. Our baby-sitter is also deaf. We communicate with her by signing, not talking. We sign together when she reads me stories. She tells me I think like a deaf person, and I like that! **EP**

Siblings Preston, Genelle and Erin wave to the camera two years ago. Everyone in the family has learned sign language.

Hold on! Genelle was interrupted while using the TTY during a phone conversation with a friend.

Preston, 6, attends kindergarten at Wilson Elementary School in Corpus Christi, Texas. He lives in Corpus Christi with his sisters, Genelle, 8, and Erin, 4, and his parents, Roger and Benna. He loves to play soccer, baseball and computer games.

Genelle, who was born profoundly deaf, is a third-grader at St. James Episcopal School, with support from a sign interpreter and a teacher certified in deaf education

The Children's Page welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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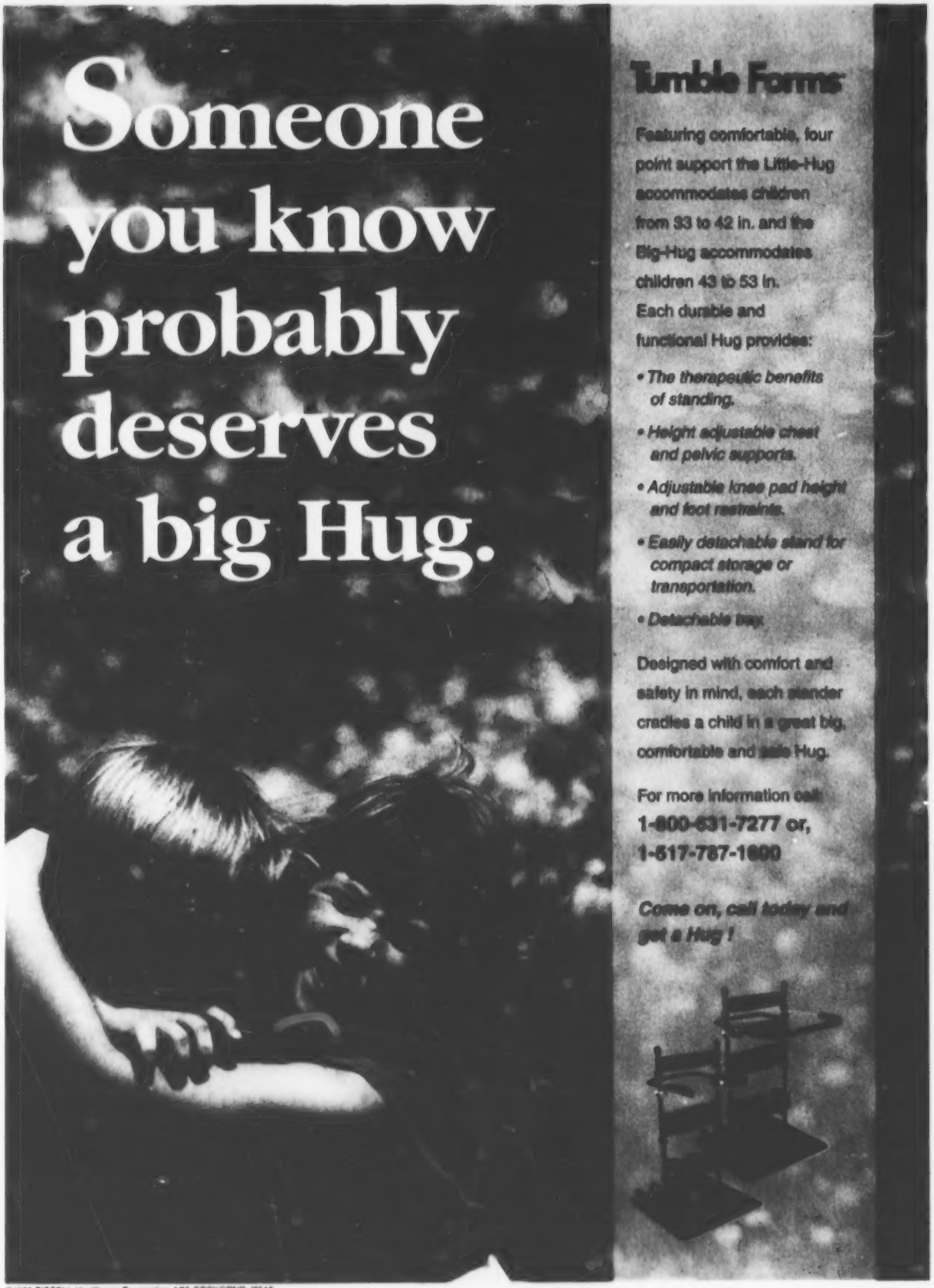
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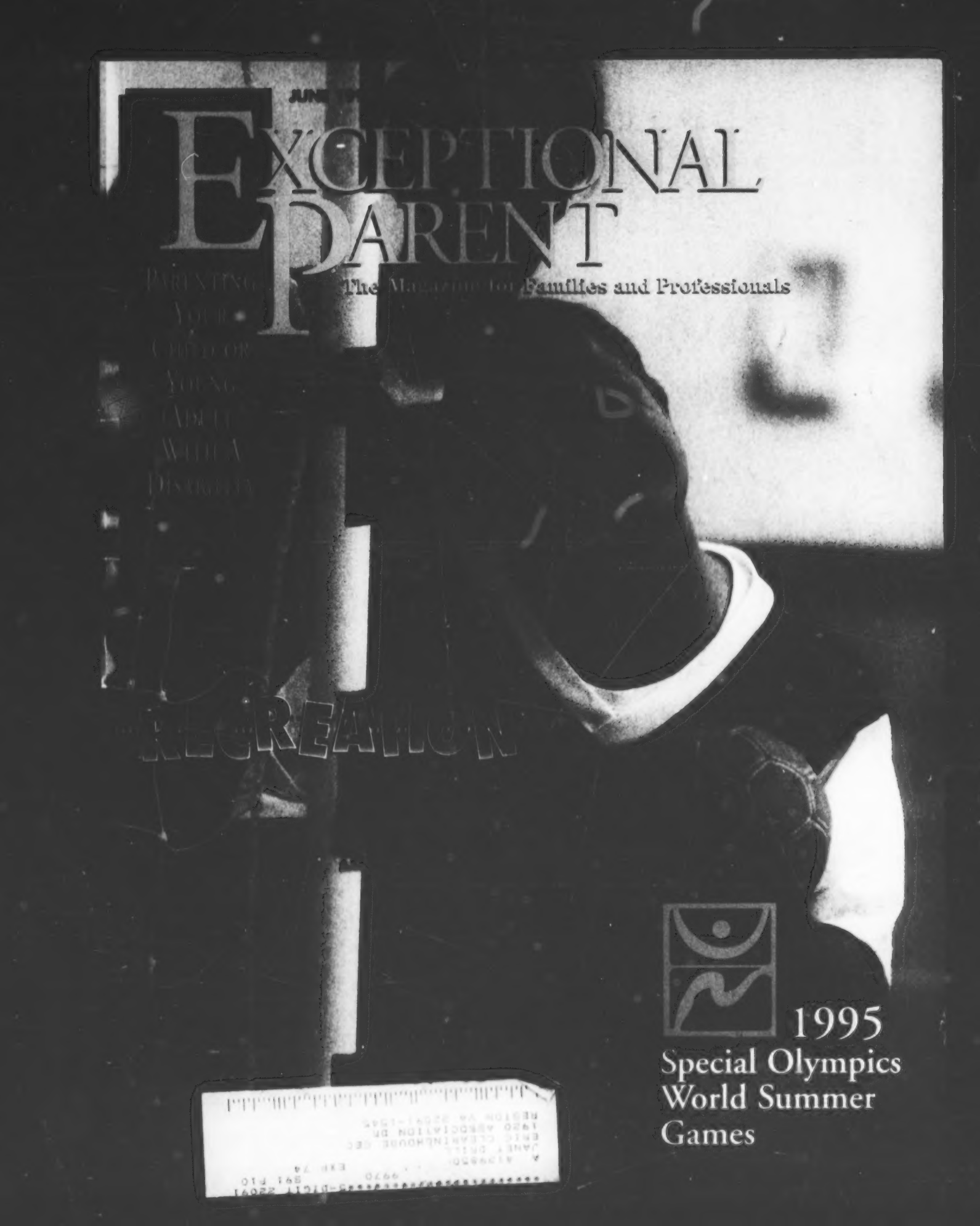
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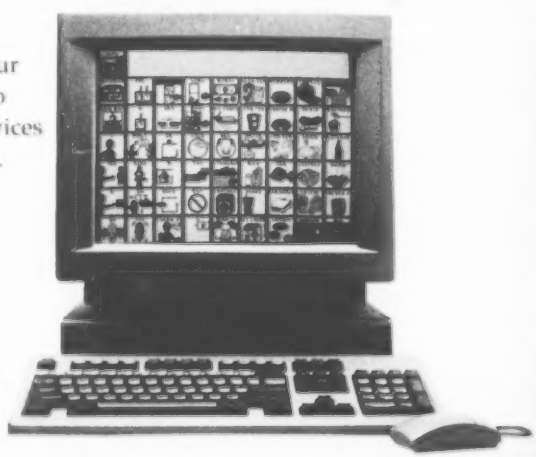

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EXCEPTIONAL PARENT

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since 1971

The Magazine for Families and Professionals

JUNE 1995 VOL. 25, ISSUE 6

PAGE 64

Cover: *Unified Sports competition, in which athletes with and without mental retardation play on the same teams, was first introduced at the 1991 International Special Olympics Summer Games with three sports and 100 athletes. Just four years later, the 1995 Special Olympics World Games, held July 1–9 in New Haven, Connecticut, will feature Unified competition involving more than 1,000 athletes and 11 sports. Read more about Unified Sports in this issue, beginning on page 56. Photo: Special Olympics Unified Sports.*

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EDITOR'S DESK

Congratulations, Special Olympics!

In 1968, the first International Special Olympics Games were held in Chicago. One thousand athletes with mental retardation—from 26 states and Canada—competed in track and field, floor hockey and aquatics. This summer, from July 1–9, at the ninth Special Olympics World Summer Games in New Haven, Connecticut, more than 7,000 athletes from some 140-plus countries will compete in 21 sports!

STANLEY D. KLEIN, PH.D.

The Special Olympics success story is like so many others—a story of the ways parents, family members, people with disabilities and advocates have changed the world for people with disabilities, their families and their communities. When Eunice Kennedy Shriver started a summer day camp for children and adults with mental retardation and encouraged their participation in a variety of sports and physical activities, many people considered her efforts "unrealistic." When you watch the Games this summer, in person or on television, or read about the Games in the media, think about that word—"unrealistic"—and how often we still hear it used in reference to individuals with disabilities. Thankfully, leaders like Mrs. Shriver and others, whose names are not so well-known, have pursued their visions and made dreams become "real."

Special Olympics has also been open to change. As "inclusion" entered our vocabulary, Special Olympics initiated "Unified Sports." See our report in this issue.

Recreation

As this issue illustrates, recreation includes a number of activities. In the past, many children and young adults with disabilities were discouraged from pursuing recreational activities. Some well-meaning people feared that an individual's self esteem might be irreparably damaged by his or her inability to "keep up" with peers in competitive activities. Fortunately, we are now learning that all people can enjoy active participation, even when their own talents in an activity may be limited. For generations, many people have enjoyed watching star athletes perform without feeling badly about their own more-average athletic abilities. Nonetheless, it seems many have needed to see the success of programs like Special Olympics to appreciate the value of participation.

Talking about disabilities

Most parents will agree that it is helpful to talk about children's disabilities with them. But it is not an easy task and there are few guidelines. As usual, however, when we asked, our readers came through to share their ideas on this topic. You can read some of their stories in this issue.

Planning ahead

In 1996, we will mark *Exceptional Parent's* 25th anniversary. As we began planning for this milestone, we welcome suggestions from readers—ideas for "special features" to include in an anniversary issue, as well as ideas for our 1996 editorial calendar. Be creative—no suggestions will be considered unrealistic!

Special advertising supplements

This is the second issue in 1995 that includes a special advertising supplement. When we collaborate with companies on these types of projects, it is because we are confident that their programs or products are, in fact, special. In April, the Rifton Company sponsored a report about the MOVE program. In this issue, The Maryland describes Abilities Plus, its new automobile and homeowners insurance programs that were specifically designed for individuals with disabilities and their families.

We are pleased that the Abilities Plus program is sponsoring the distribution of *Exceptional Parent* at the Special Olympics World Summer Games. We look forward to meeting many of our readers at the Games and joining them in cheering for the athletes and volunteers from throughout the world.

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The Magazine for Families and Professionals

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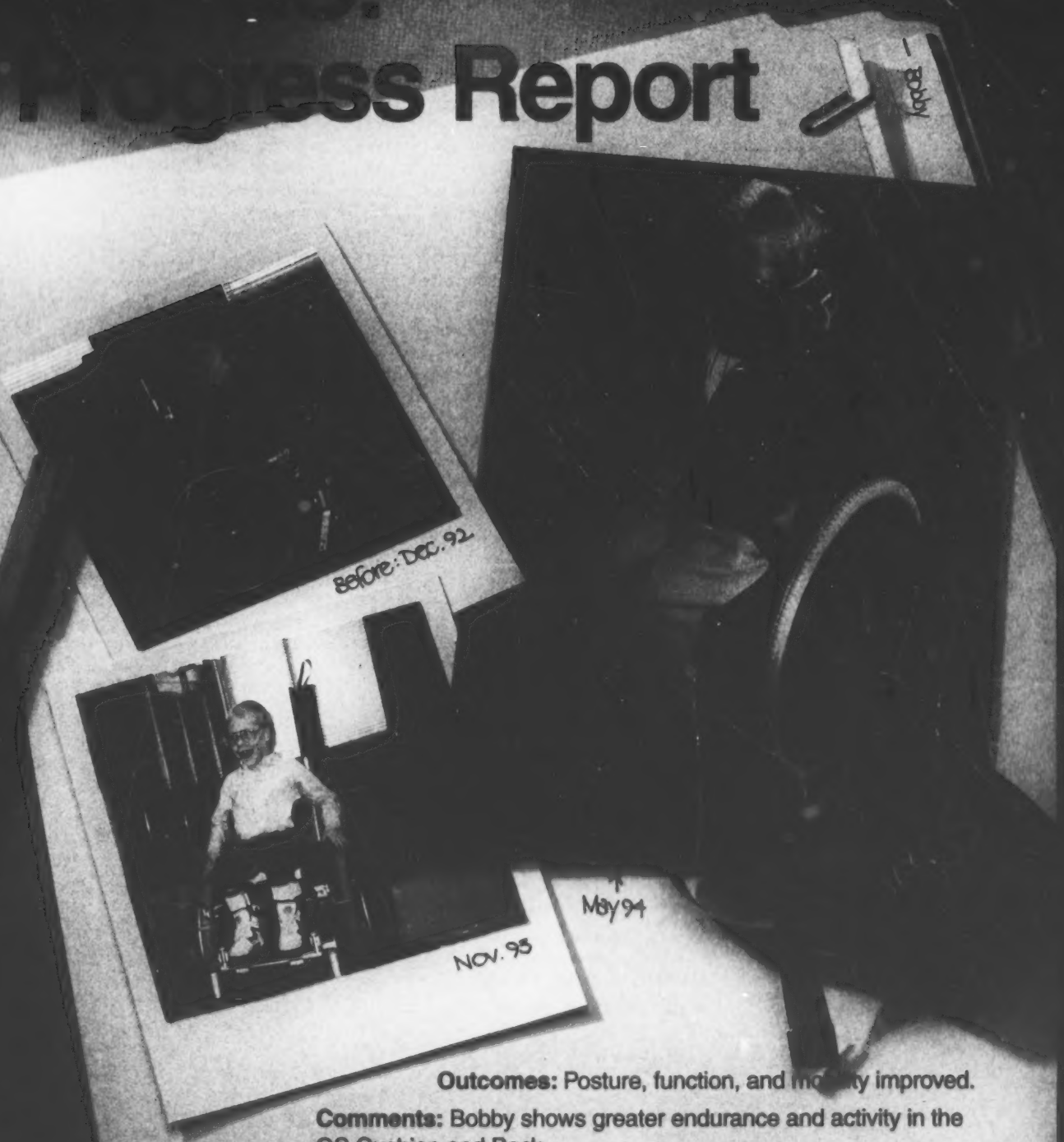
For subscription and advertising information, see page 122. BPA International Consumer Magazine Membership Applied for August 1993.

Progress Report



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LETTERS

Mental Retardation?

Last week, I picked up a copy of *Exceptional Parent* at my son's school. As I glanced through the magazine, the words "mental retardation" stood out on a page in the Exceptional Parent Library listings. I found this phrase to be very offensive.

I have a child who is both physically and mentally impaired. "Impaired" seems to be a very accepted word and sounds much nicer than "retarded." I think the editors should consider this and change this category of books to "Mental Impairment." I know this would make the magazine more appealing to me.

K.S., Michigan

EDITOR'S NOTE: There are no uniformly acceptable terms for many kinds of disabilities. Foremost, however, we are advocates of using "people first" language—that is, always referring first to the child or adult, then to the disability (for example, "a child with epilepsy," not "an epileptic child." In keeping with this perspective, we do not use "disabled" or "retarded" or "impaired" as a noun (such as referring to "the needs of the disabled"). I always try to speak this way as well, even though it can sound awkward at times.

I prefer to use the term "mental retardation," rather than "mental impairment," because it is important to make a clear distinction that mental retardation and mental illness are two different disabilities. The term "mental impairment" does not make this distinction clear. While some people have both mental retardation and mental illness, most people with mental retardation are not mentally ill. Similarly, most people with mental illness are not mentally retarded. People with both disabilities have suffered because the general public lacks information about this distinction.

There are also some parents and professionals who do not believe we should use any labels—believing that any label can lead to discrimination. Sadly, that is sometimes true. However, I believe that "labels" can also lead to greater understanding of individual differences, and can help family members and people with disabilities connect with one another.

—S.D.K.

Epilepsy—Ketogenic Diet

I'm writing to express my disappointment in the March 1995 issue of *Exceptional Parent*, which focused so much attention on epilepsy without even mentioning the ketogenic diet.

Our three-year-old son, Ben, began having seizures at 10 months of age. These were diagnosed as infantile spasms. Even after two courses of ACTH (adrenocorticotropic hormone) and trials of every anticonvulsant in every possible combination, Ben's seizures continued to worsen.

continued on page 8

EXCEPTIONAL PARENT
Parenting Your Child or Young Adult With a Disability
The Magazine for Families and Professionals

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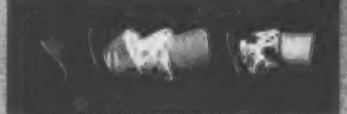

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continued from page 4

He was finally diagnosed with Lennox-Gestaut syndrome.

Ben experienced tonic, tonic-clonic, atonic (drop attack), myoclonic and atypical absence seizures—more than 100 seizures every day. His EEG (electroencephalogram) was profoundly abnormal. Ben was also becoming increasingly withdrawn, lethargic and delayed, and was developing many autistic-like behaviors.

The doctors held out little hope of ever getting our child's seizures under control. Through a friend—one I made as the result of a *Search* letter—we heard of the ketogenic diet. Having no other course of treatment left to try, we decided to investigate it.

On November 1, 1994, our son was admitted to the hospital and placed on the ketogenic diet. Within two weeks, he was seizure-free and off all his medications. On February 21, 1995, Ben had an EEG—and the results were normal! Even his neurologists were amazed.

It's been more than six months since Ben's last seizure and I feel I must share this with others. We are very fortunate that this treatment was available to us, and I know there must be other children who may benefit from this diet.

Ben is still quite delayed, but is making steady progress. Most importantly, he is happy and safe. That's all we ever wanted, really. The ketogenic diet was the light at the end of a very long, dark tunnel.

D.S., New York

EDITOR'S NOTE: The Epilepsy Foundation of America (EFA) stresses that the ketogenic diet—a very restrictive high-fat, low-protein and -carbohydrate regimen—is in no way a "do-it-yourself" treatment. The diet must be initiated in a hospital setting under medical supervision and followed strictly thereafter, with frequent medical checkups. EFA notes that following the diet requires a truly dedicated team of health professionals and family members.

The JOHNS HOPKINS KETOGENIC DIET FACTSHEET explains that the diet has typically been used with children who have uncontrolled myoclonic, atonic and tonic-clonic seizures. Some studies suggest it is less effective for partial or focal seizures, or for absence or petit mal seizures. However, it is impossible to predict which children will experience seizure control with the diet; many studies suggest that more than 50 percent of children with uncontrolled seizures will be helped considerably.

continued on page 15

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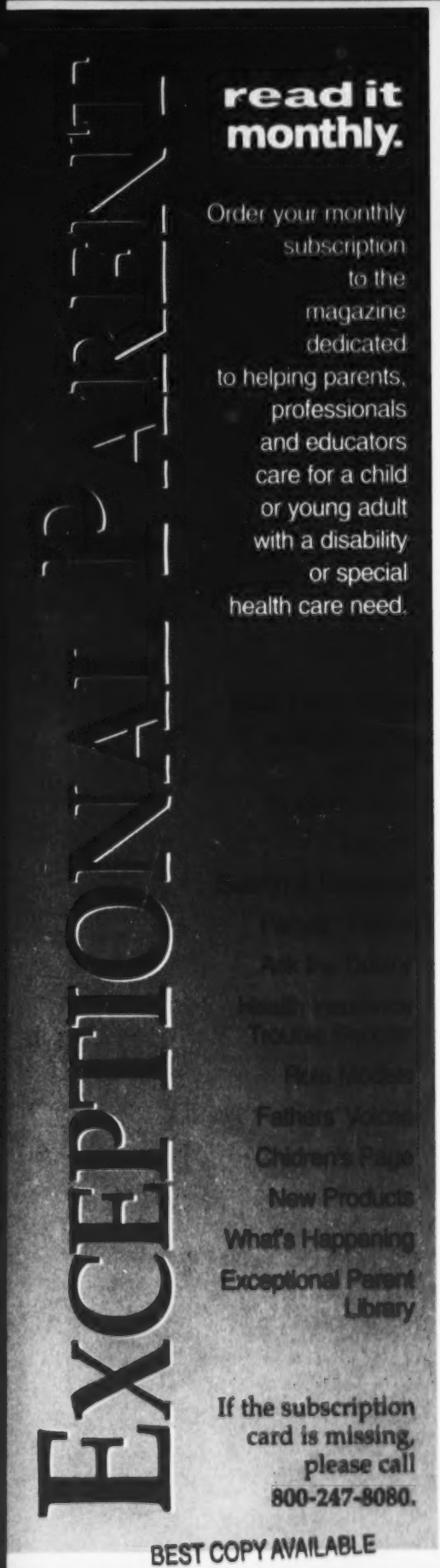
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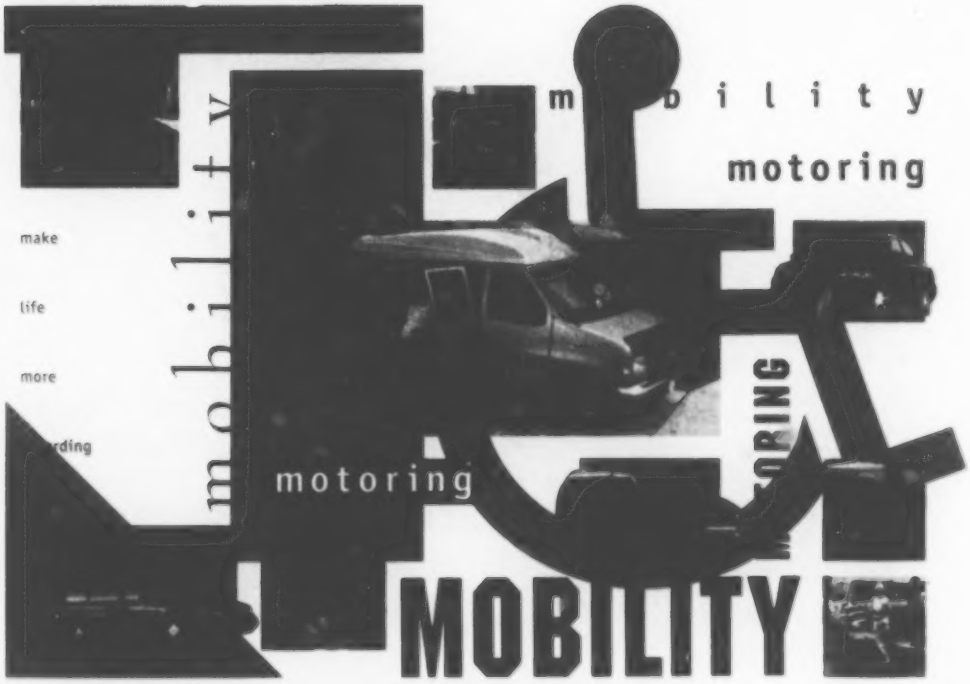

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So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call **1-800-952-2248** (for TDD users: **1-800-TDD-0312**). You'll discover that Mobility Motoring is your kind of reward!

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[2] *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance Plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.*

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Circle #180

continued from page 8

The diet is used most often with children aged two to six. It is difficult to implement and maintain in children younger than two, while children older than six often rebel at its restrictions. The diet is typically continued for at least three years.

For more information, EFA recommends the following resources:

- *THE EPILEPSY DIET TREATMENT: AN INTRODUCTION TO THE KETOGENIC DIET (paperback, 1994, 180 pp.): Written by medical professionals at Johns Hopkins; Demos Publications, 386 Park Ave. S., Ste. 201, New York, NY 10016; (800) 532-8663; $21.95.*
- *AN INTRODUCTION TO THE KETOGENIC DIET: A TREATMENT FOR PEDIATRIC EPILEPSY (video, 45 min.): The Charlie Foundation, 1223 Wilshire Blvd, Box 815, Santa Monica, CA 90403; free (send card with name and address).*
- *THE JOHNS HOPKINS KETOGENIC DIET FACT SHEET (factsheet, 4 pp.): The Epilepsy Foundation of America, 4351 Garden City Dr., Landover, MD 20785-2267, (800) 332-1000; free.*

More Vacation Memories

We just received our April 1995 issue and were happy to see Mickey Mouse on the cover, but not so happy that we didn't get our vacation story and snapshots off to you in time. We ended up with too many appointments in February and missed the deadline. If you could run this letter with Bryant's picture I know he'd be so happy!

We have been to Disney World three times and are planning to go again. Bryant's 180-pound power wheelchair makes flying difficult, so we drive. We pack up all his supplies, which can be quite a trick! He eats by g-tube, and one trip means about three cases of Pediasure. Bryant has a tracheostomy and needs humidity at night, so we also need to bring his compressor and humidity "collar."

Anyway, if we could say anything to other readers, it would be this: Go to Disney World if you've got the chance! Bryant spent three years on life support and could not leave our house except for medical emergencies—unfortunately, those were plentiful. But now that life has stabilized, we enjoy every possible moment.

Of course, there is more to life than Disney World, but the feeling we get from going there and the way the Disney people handle kids with special needs is beyond any place we've ever seen. They have gone out of their way for us and for Bryant each time we've visited. We have met Disney characters—including Snow White, Peter Pan and Alice-in-Wonderland—at a Disney character breakfast. Later on, they remembered Bryant by name and came over to greet him during the parade! I could go on and on—and wish I had done so for the vacation issue.

It's an incredible feeling to watch a child who had been critically ill having the time of his life. If you can see your way clear to go, it's worth the trip! Make sure you write to Disney first and explain your family's special needs. They will accommodate you—especially at the on-site hotels—and will make every effort to make your child's visit special.

I *don't* work for Disney, really!

Cheryl Paquette, New Hampshire

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Dave Paquette and children Bryant, 6, and Emily, 3, enjoy meeting Winnie the Pooh during a trip to Disney World.

For more information on Apple products, contact us at 800-600-7808, 800-755-0601 (TTY), or on the Internet at applewdsg@eworld.com.

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PEOPLE WITH SPECIAL NEEDS HAVE SPECIAL AUTO INSURANCE NEEDS

Janet was on the way to a physical therapy appointment with her son, Matt, when suddenly, another car ran a stop sign and... C-R-A-S-H! Fortunately, Janet and Matt escaped unharmed, but their van was damaged and undriveable.

When the tow truck arrived, another nightmare was just beginning. How would Janet get Matt up into the tow truck? Even if she could, would he be safe? What would she do with Matt's power wheelchair?

Then there was the question of the damaged van. Was her adapted vehicle properly insured? Would she be able to rent another accessible van while hers was being fixed? And would her insurance policy cover the additional cost?

Enjoying a summer outing are (clockwise from left) Rob, Laura, Jeff and David Glushakow. Laura spends much of her spare time transporting Jeff and David to sports practices, art classes and other extracurricular activities in the family's adapted van. "If our van were stolen or in an accident and had to be repaired, our lives would come to a virtual standstill," she says.

What would you do?

What would *you* do if you were out with a child who uses a wheelchair and your vehicle broke down? Would your insurance company pay for the additional cost for special transportation to get you and your child home?

What would *you* do if your vehicle were damaged in a collision? Would your insurance company cover the cost of repairing the special adaptive equipment you've added? Is your insurance company even aware of the equipment you've added?

Would your insurance cover the higher cost of renting an accessible vehicle if your car or van were in an accident and needed to be in the repair shop for a few days? Or a few weeks?

Could this happen to you?

Linda is a busy mother who lives in Baltimore, Maryland with her husband, Dennis, 19-year-old son, Tony, and 15-year-old daughter, Tina, who uses a power wheelchair. When Tina isn't studying, racing, playing basketball or swimming, she and her mother are often on the road, traveling to and from Philadelphia, where Tina sees a number of doctors and therapists.

"I worry about what we would do if our van broke down," admits Linda. "How would I get help? And what would Tina do? I guess we would just have to get out, and walk and roll to a phone."

A company that cares about special needs

Most insurance companies don't realize that some of their customers have special needs. Or they don't want to think about special needs—because that would mean spending a lot of time, effort and money designing entirely new programs for a small percentage of their customers.

"The Maryland Insurance Group is the first corporate sponsor of a Special Olympics Family Program at the state level in the United States, as they are now the sponsor of the Maryland Special Olympics Family Program. With the "ABILITIES PLUS" program, and their close involvement with families in Special Olympics, the Maryland Insurance Group has certainly taken a leadership role in providing exceptional caring services to families with special needs children."

—Jim Santos, Family Director
Special Olympics International

Most insurance companies develop policies, then search for people to buy them. The majority of their customers have typical abilities and needs. But what about the millions of people in the United States today who have some type of disability? And what about the people who care for them or transport them? Who has addressed their needs?

No one. Until now.

The Maryland developed ABILITIES PLUS, not because the law requires them to (it doesn't), but because they care and it's the right thing to do.

At The Maryland, they have not only thought about people with disabilities, they have spent the last two years talking with men, women, teenagers and children throughout the United States, finding out what customers with special needs want and need. Now they've designed an insurance program to meet those needs. They call this program ABILITIES PLUS.

Could this happen to you?

Helene and Jack, a California couple, are facing a dilemma. "Like all of her friends, our 18-year-old daughter, Beth, wants to get her driver's license—and we don't blame her. But frankly, we've been avoiding the subject," says Helene. Beth has been using a manual wheelchair since a diving accident seven years ago left her a paraplegic.

"Who would insure her? Even if she could get coverage, the

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"ABILITIES PLUS—what a phenomenal program! Light years ahead of your contemporaries—on the cutting edge!"

—Patricia McGill Smith, Executive Director
National Parent Network on Disabilities

cost would probably be astronomical. We haven't even mentioned the possibility to our insurance company," Jack adds.

Could this happen to you?

"We are an extremely busy family," says Laura, who runs a household, works part-time outside of her home and, along with husband Rob, transports their two sons, Jeff and David, to baseball practice, art classes and a variety of other appointments and activities in the family's adapted van. Ten-year-old David, who has muscular dystrophy, uses an electric wheelchair.

"If our van were stolen or in an accident and had to be repaired, our lives would come to a virtual standstill. David and his wheelchair couldn't go anyplace," Laura says.

A company that listens

The Maryland has listened to the personal experiences, concerns and frustrations of hundreds of people with disabilities, their families, their caregivers and leaders of national organizations and associations. And in the process they discovered something very interesting—in addition to their special needs, safety and security are more important to people with disabilities than to most people. They pre-plan their travel, drive fewer miles and appear to have fewer accidents. They take good care of their homes and property, often equipping them with special safety features for added protection. And they are more likely to follow manufacturer recommendations for regularly scheduled vehicle maintenance.

The Maryland wants to change cutomers' traditional perception of insurance companies.

Think for a moment. When was the last time an insurance company offered you a program or service *designed especially for you*—a program that takes into account that you or someone you love has a disability?

When was the last time an insurance company sought out your business and promised to work with you to further develop and enhance their coverages and services to meet your needs, now and in the future?

continued on page 20

"ABILITIES PLUS targets a previously ignored market of people with disabilities and their families who can benefit from having protection or security from the financial hazards associated with auto travel—a significant aspect of our liberty!"

—John D. Kemp, Executive Director
United Cerebral Palsy Associations

THE MAN BEHIND THE SCENES...

Patrick Favale

Director, ABILITIES PLUS Program

On Christmas Eve, 1969, Patrick A. Favale, a Sergeant in the U.S. Army, was critically wounded in Vietnam. He spent the next 11 months in the hospital, recovering and adjusting to his injuries. In addition to receiving a Purple Heart, Pat was twice decorated. Although his wounds left him with a disability, Pat went on to marry and raise a family. He has spent the past 18 years working in the insurance industry, where he has met with great success.

Pat Favale (right), shown here with wife Barbara and twin sons David and Jason, 19, says that developing the ABILITIES PLUS program was one of the highlights of his professional career. "This was the first time in my career that I've been able to integrate 25 years of experience as a person with a disability and 18 years as an insurance professional to help others in the disability community," Pat says.

Two years ago, Pat was given the special assignment of answering this question: What if The Maryland were to develop a program that would specifically meet the needs of people with disabilities? "I considered it a privilege to be put in charge of such an important project," Pat says. "What made this so special is that this was the first time in my career that I've been able to integrate 25 years of experience as a person with a disability and 18 years as an insurance professional to help others in the disability community."

Pat began with an exhaustive search for information about people with disabilities in relation to the insurance industry. He found very little. Pat recalls, "I did find out one thing. Everyone told me I was the first person from an auto and homeowner insurance company to ever ask about the special needs of people with disabilities and those who care for them." Pat realized that the only way he was going to gain a better understanding of individuals' special needs was to go out and meet people personally. And that's exactly what he did.

For the past two years, Pat has traveled thousands of miles across the country, has attended numerous meetings and conferences and has talked with hundreds of people with disabilities, family members, caregivers and leaders of national organizations. Early on, working with the Maryland Special Olympics and conducting a survey of the National Amputee Golf Association gave Pat an appreciation of the lifestyles, obstacles, frustrations, needs and concerns of individuals with a range of disabilities.

As a result of the information Pat gathered, The Maryland created ABILITIES PLUS, the first automobile and homeowners insurance program that addresses—rather than ignores—the needs of people with disabilities. Reflecting on two very busy years, Pat says, "During the last two years, my life has been enriched beyond measure. I have had the privilege and pleasure of meeting the most incredible and inspirational group of people one could ever hope to meet in a lifetime. And even though this was a very challenging time for me, my project team and the company, it was time well spent—because the vision we had two years ago is now a reality."

Pat is much more than an insurance professional; he's an advocate. "People with disabilities are currently underserved in many areas, especially insurance," he says. "The ABILITIES PLUS program has the potential to revolutionize the automobile and homeowner insurance industry and finally give people with disabilities and those that care for them the coverage and services they need... and the peace of mind they deserve."

The tow truck is here. Now

How do I get my son home safely?

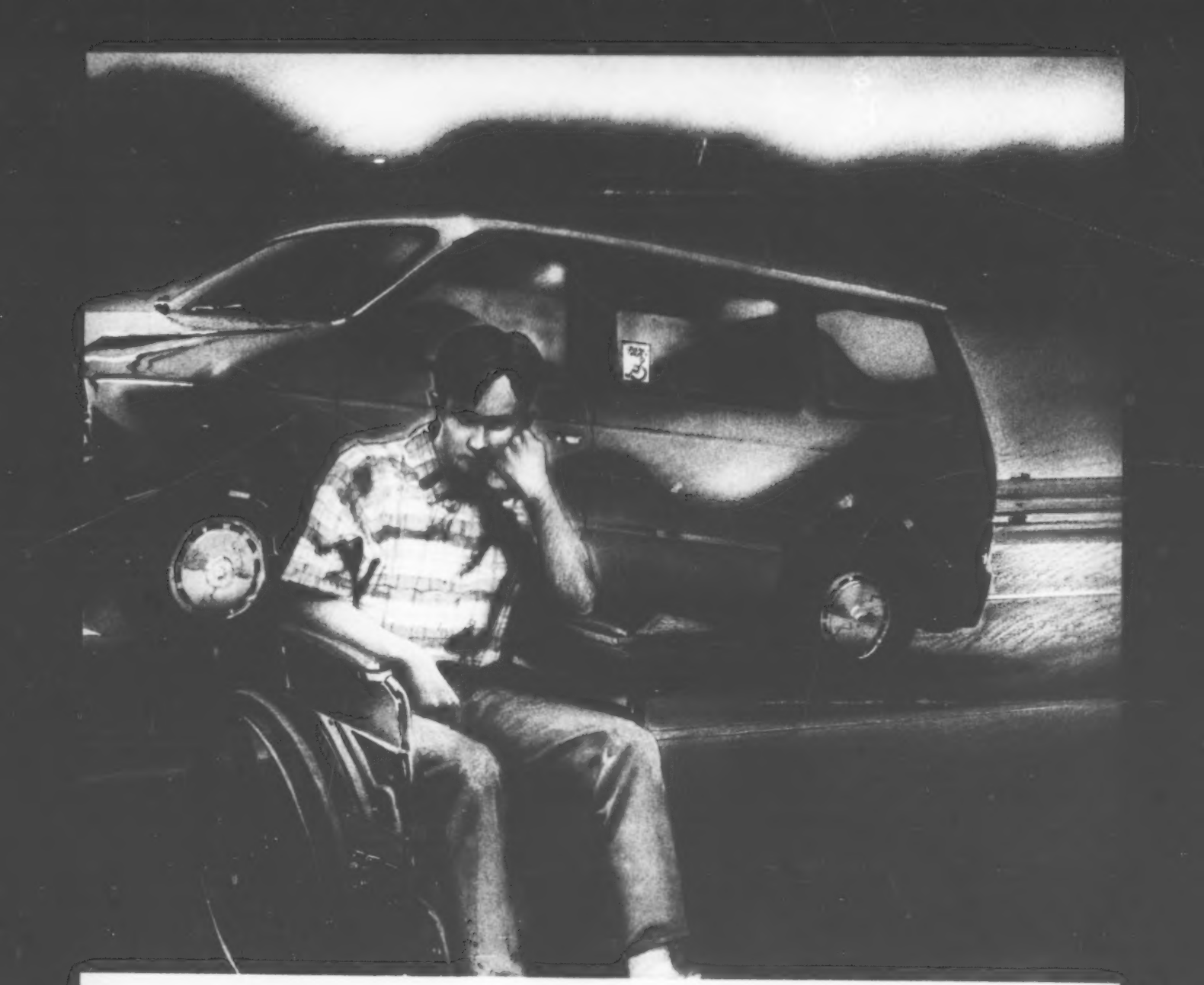
Abilities Plus takes care of your vehicle *and* your son. It reimburses you, up to a dollar limit, for the cost of the special transportation *he* needs, too.

Is my van properly insured?

Abilities Plus also expands your coverage so that your vehicle, with its special modifications, can be repaired.

How do I get another van?

You can rent the kind of replacement vehicle you need, because *Abilities Plus* doesn't restrict you to a daily dollar limit like most policies. Instead, it provides an aggregate benefit which gives you greater flexibility.



what?

Abilities Plus is comprehensive insurance for people with special needs. It's Roadside Assistance, access to a dependent care network, and many other services that add value for our customers.

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For more information, call

1-800-222-2788.

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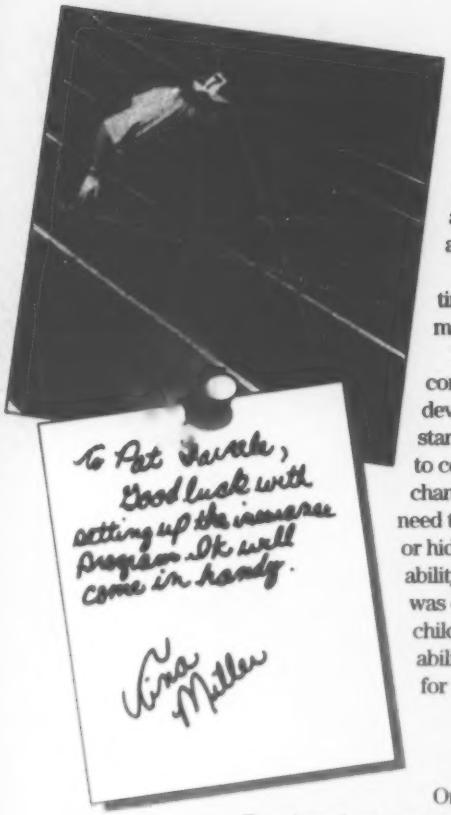

When was the last time an insurance company asked you if you had the right kind of coverage for your vehicle and home—and any special equipment or adaptations?

And when was the last time an insurance company made you feel *welcomed?*

The Maryland is a caring company committed to developing a better understanding of its customers and to continually meeting their changing needs. You don't need to withhold information or hide a family member's disability—because ABILITIES PLUS was designed especially *for* children and adults with disabilities and those who care for them.

What exactly is ABILITIES PLUS?

On one level, ABILITIES PLUS is unique coverage designed especially for you and the people you care for. On another level, it's comprehensive automobile and home insurance at a competitive price. It provides outstanding customer service and rapid, fair claims settlement—the kind of service you should expect from any insurance company.

• *Tailored Auto Protection:* When you purchase your basic policy from The Maryland you can choose the additional coverages you need from the ABILITIES PLUS program. ABILITIES PLUS was created for people who use wheelchairs and have modified vehicles, and those who have other special needs that require different types of coverage than those offered by other insurance companies.

• *Special Towing and Labor Coverage:* If your vehicle is in an accident or breaks down and must be towed, this enhanced benefit reimburses you up to $75 per breakdown for the cost of special transportation needed for the person with a disability.

• *Special Extended Transportation Coverage:* If your vehicle is involved in an accident and needs to be repaired, ABILITIES PLUS offers coverage that gives you greater financial flexibility to rent a vehicle with the special equipment you need—more dollars per day toward the rental cost of a replacement vehicle.

• *Special Customized Equipment Coverage:* The higher cost of repairing or replacing your modified vehicle can be covered under ABILITIES PLUS.

"The Abilities Plus program offered by The Maryland is a significant step... and few businesses have recognized the opportunity to market specialized programs. I applaud The Maryland's initiative."

—Kent Waldrop, Founder and President
Kent Waldrop National Paralysis Foundation

"The ABILITIES PLUS program recognizes the unique needs of people with disabilities, and by providing for such needs, gives [them] their equal status in society."

—Ross Catalano, Executive Director
National Association of People with Disabilities

The Maryland doesn't want to meet your expectations; it wants to exceed them.

That's why their offices are staffed 24 hours a day, 365 days a year. When you call, you'll speak with a person, not a machine, a patient, competent person who will respond to your questions and problems with understanding and sensitivity.

The professionals at ABILITIES PLUS have two goals in mind—to get you back into your car or home safely and help you get your life back to normal as quickly as possible.

"ABILITIES PLUS mirrors the mission of Special Olympics' 27-year history—the empowerment of people... This insurance product uniquely addresses the underserved needs of families and people with disabilities.

"The ongoing commitment of The Maryland Insurance Group to the community with disabilities is not simply evidenced in this product. Maryland Special Olympics is proud to recognize their commitment to our local program as well as... financial support, leadership and employee volunteer participation.

"This is clearly a marriage of enormous corporate citizenship tied to a product whose time has surely come."

—Patricia Krebs, Ph.D., CEO
Special Olympics of Maryland

More for your money

ABILITIES PLUS also offers you these value-added services:

• *Roadside Assistance:* 16,000 garages throughout the country are ready to assist ABILITIES PLUS customers at special reduced rates.

• *Guaranteed Auto Repairs:* To make sure you get the best claim repair service possible, ABILITIES PLUS has organized a network of auto repair facilities whose work is guaranteed for as long as you own your vehicle.

• *Dependent Care Network:* If you need to be away from home for a few hours or overnight, as an ABILITIES PLUS customer you can get a referral to qualified help at a spe-

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cial discount. One toll-free phone call is all it takes to get a homemaker, personal care assistant or other home health professional.

• *Information about Disabilities:* How do you find out about specific disabilities and support groups? Where can you learn about the availability of vocational training programs for young adults with disabilities? How can you get information on assistive technology? Access to a wide range of information resources is only a toll-free phone call away.

• *Mail Service Pharmacy:* You get reduced rates on brand-name or generic mail-order drugs for the treatment of chronic illnesses or conditions.

• *Telephone Calling Card:* A discounted phone card saves you money on long-distance credit card calls.

Tina Miller, 15, shown here with parents Linda and Dennis, and brother Tony, 19, is a typical active teen. Along with her participation in a variety of sports, Tina and her mom spend a lot of the time on the road, traveling back and forth from their Baltimore home to appointments with medical specialists in Philadelphia. "I worry about what we would do if our van broke down," admits Linda. "How would I get help? And what would Tina do?"

A commitment to future development

At present, ABILITIES PLUS may not be able to meet everyone's special needs. But The Maryland is committed to the continued development and enhancement of ABILITIES PLUS via direct input from people within the disability community. The Maryland looks forward to hearing from you so ABILITIES PLUS can continue to expand its capabilities—caring for your special needs.

"The first of its kind... needed by thousands... your company is a champion of people with disabilities."

—Nita Savader, Ph.D., Executive Director
Association for Special Kids, Inc.

We can't end discrimination against people with disabilities, or change the physical environment. But ABILITIES PLUS can make everyday life a little easier, safer and more comfortable.

To get more information or to ask for free quotes on your automobile and home insurance, call The Maryland at 1-800-222-2788, or mail in the postage paid reply card provided. You can also write: c/o Patrick A. Favale, ABILITIES PLUS, P.O. Box 1228, Baltimore, MD 21203-1228 and tell him what you think about the program and about your special needs.

If this program doesn't apply to you, maybe you know someone who could benefit—a friend, a relative or an organization. Won't you pass this information along so ABILITIES PLUS can provide quality coverage and service for the people who can use them the most?

Frequently Asked Questions About ABILITIES PLUS

Q. Who is eligible for the ABILITIES PLUS Program?

A:
- People with disabilities.
- People who care for family members who have a disability.
- Employees of human service organizations who use their private vehicles to transport people with disabilities.

Q. I already have car insurance. Won't that cover any damage my modified van would sustain in an accident?

A: Not necessarily. Check your policy. If you've added adaptive equipment, such as a wheelchair lift, raised roof or customized control devices, your insurance company isn't obligated to cover the cost of fixing or replacing them unless they are properly covered under your policy.

Q. What's the difference between my current auto policy and ABILITIES PLUS if my vehicle breaks down?

A: ABILITIES PLUS can guarantee to reimburse you up to $75 toward the cost of special transportation needed to get you and the person with a disability to a safe place any time your vehicle breaks down away from home.

Q. Is the program reasonably priced?

A: You may be surprised how reasonable the cost is. Why not call the toll-free number and ask for your no-obligation automobile and homeowner quotes?

Q. Is ABILITIES PLUS available in my state?

A: Coverage availability varies by state. We are continuing to add additional states each month.
Even if ABILITIES PLUS is not yet available in your state, we are eager to hear from you and every other interested consumer for three reasons:

1. We want to send you information about ABILITIES PLUS.
2. We want input about ABILITIES PLUS from consumers everywhere. We want to meet your insurance needs and find new ways to serve you.
3. We want to be able to contact you when ABILITIES PLUS becomes available in your state.

Q. Are there any special requirements to apply for ABILITIES PLUS?

A: No. Just call 1-800-222-2788 or mail in the postage paid reply card provided. You can also write: c/o Patrick A. Favale, ABILITIES PLUS, P.O. Box 1228, Baltimore, MD 21203-1228 and share your thoughts.

Abilities PLUS℠ *Available exclusively from* **The Maryland Personal Insurance**

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Unparalleled Normalcy

Unsurpassed Performance

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- Moderate to Heavy Absorbency
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- Fitted Liner
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Skin Care Pack contains SlimLine® Booster Pads, SlimLine® Adjustable Briefs, SlimLine® Fitted Liners, and SlimLine® Peach Sheet Care Pads.

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Circle #117

LETTERS

continued from page 15

Definitions, Please!

I have been receiving your magazine for about one year and find many of the articles helpful and interesting. I even initiated a "Search" letter which received a few responses.

However, I have one suggestion which I am sure many other readers would also appreciate. The articles and departments—especially *Search* and *Respond*—contain many names of specific conditions or other words that are unfamiliar to those of us who have children with other disabilities. It would be helpful to have some kind of glossary at the end of the magazine in which these terms could be defined.

I noticed that in the April 1995 issue some definitions were given, usually in parentheses after the name of the condition, and that the *Ask the Doctor* column provided excellent definitions for conditions and medications. I found this very helpful in visualizing the situation that was described. I would like to see more of this throughout the magazine.

Your magazine has provided me with some valuable information and I have recommended it to several other parents of children with disabilities. Keep up the good work!

M.S., California

EDITOR'S NOTE: We're glad you've noticed our recent attempts to provide definitions for specialized terms. These efforts continue with this issue and we would appreciate reader feedback on how we are doing. Rather than a glossary, we are attempting to define terms within the context of their appearance or, in some cases, with a sidebar (as in this issue's FATHERS' VOICES). We appreciate when people writing SEARCH and RESPOND letters provide definitions of the terms they use; this can save us the time it would take to obtain this information from other sources.

479

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Circle #246

481

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Circle #14

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Circle # 41

Rifton

484

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SEARCH

Chromosome 14q+

I am a parent of a seven-year-old boy who has been diagnosed with the chromosomal abnormality 14q+ (the addition of chromosomal material to the long arm of chromosome 14). The origin of the additional chromosomal material has not yet been identified. James was born with a low birth weight, a club foot, an eye syndrome and microcephaly (a small head). The doctors told me James would probably be developmentally delayed.

James' growth rate has been slow. He has nighttime feedings through a g-tube. He is on a strict feeding program to encourage him to take more food by mouth. His development has been slow, but he progresses steadily.

I would like to know if there is another child, somewhere in the world, who has the same chromosomal abnormality or any of the same symptoms.

R.B., Ontario, Canada

Alpers Disease

My 20-month-old daughter, Kristin, has been diagnosed with Alpers disease, or progressive infantile poliodystrophy, a terminal illness. I am searching for another parent or family with a child with this disease.

M.A., Georgia

Foix-Chavany-Marie Syndrome

My son, Austin, is five years old. Last summer, he was diagnosed with a rare disorder called Foix-Chavany-Marie syndrome. Some of the hallmarks of this syndrome are mild mental retardation, poor motor skills, no speech and a pleasant personality.

Austin has developmental dyspraxia (difficulty with planning and performing coordinated movements), low muscle tone, poor gross and fine motor skills and no speech. He does vocalize and uses sign language to communicate. Due to his fine motor difficulties, Austin's signing is not exact. We are trying to get funding for an augmentative communication device.

We want to find other children or adults who have the same problems as our child.

J.B., Kansas

Tell us about...

... your child's favorite toy or playtime activity. (Have you found ways to adapt toys or play activities so your child can participate more easily?)

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.

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Circle #224

485

Feeling Isolated

Our four-year-old daughter, Katie, has been diagnosed as having pervasive developmental disorder (PDD), or developmental delays with autistic characteristics. We first became suspicious that something was wrong when she was about 18 months old. Before that age, although she never spoke any words, she babbled. She waved and pointed and played a little with toys. She would go get her diapers when we asked. Her eye contact was normal.

But by two years of age, she had stopped making sounds and had developed an awful temper. She would gather up toys and then just walk around endlessly holding them. She would let us hold her, but she was just as happy to be alone.

An EEG, CT scan and hearing tests were normal.

Katie's eye contact continues to improve and she is again very lovable. She smiles and laughs a lot. She loves to be with her brother and other children. However, she still doesn't talk. She signs "eat" and "more." We have a communication book, but she doesn't use it. She slaps her chin when she wants to communicate. Sometimes these slaps are soft and teasing, but when she's frustrated, she slaps pretty hard.

Katie continues to have hardly any interest in toys. She just picks them up and drops them. Her motor skills are a little delayed and she is just now starting to use utensils with help. When Katie is anxious or tired, she alternates loud and heavy breathing with holding her breath. Potty training is just not coming, either. She wants to eat constantly!

Katie seems to understand so much more than she can tell us. She may not get her shoes when asked, but we'll catch her glance at them. In fact, she often glances casually at what we are talking about.

We live in a rural area and our school is helping as much as they are allowed to, but that help isn't consistent enough. Does anyone have a child like Katie? We are at the end of our rope. We feel so strongly that with more help, Katie could do so much more; we are just so alone.

K.H. & E.H., Idaho

Undiagnosed

After a variety of genetic tests by a wonderful team of medical professionals, our 21-month-old son remains undiagnosed. I can't imagine our child is the only one out there with the following birth defects. He was born eight weeks premature but was large for his gestational age (five and a half pounds). An amniocentesis had revealed kidney problems, but no chromosomal abnormalities.

continued on page 30

Transport your child safely & securely

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The E-Z-ON VEST is a dynamically tested safety restraint designed for any kind of physical or behavioral need.

Used with our mounting straps, it is easily installed in any family vehicle, bus, or wheelchair. Available in 8 sizes...toddler through adult.

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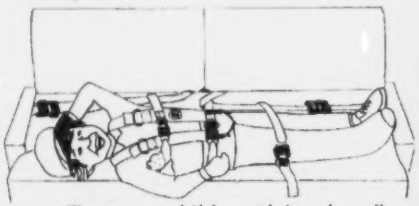

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Children with certain physical conditions (body cast, long leg cast or hip spica) have to ride in a prone or supine position. The new modified E-Z-ON VEST (Model #101M-2) enables these children to be transported securely. No special installation is required...the Modified E-Z-ON VEST adapts to the vehicle's existing seat belts.

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Circle #250 486

continued from page 29

Immediately after birth, Clifford was diagnosed with the following conditions right hydronephrosis with reflux (an obstruction of the urethra in which urine flows backward, from the bladder to the pelvis, causing pelvic swelling) and pseudo-prune belly syndrome (having the appearance of prune belly syndrome, a condition in which abdominal musculature is missing and the urinary tract is malformed), an abnormal aortic cardiac valve, cataracts, high palate and brain anomalies (decreased volume of cerebellum and thin corpus callosum). Clifford could not be weaned off the respirator in the NICU but when taken off with do-not-resuscitate orders, he amazingly, figured out how to breathe. A poor suck/swallow reflex necessitated gastrostomy tube placement.

At 21 months, Clifford is off the g-tube, but has many developmental delays, poor muscle tone, no eyebrows, hearing loss due to atresia (absence) of the ear canals, very limited weak vocalizations due to a seriously narrowed trachea and dysmorphic facial features. Constant congestion affects his daily breathing and sleeping. In spite of daily antibiotic use, doctors say Clifford's sinus and ear cavities are totally infected. He will probably need surgeries for these infections.

Doctors have done various blood studies and a skin biopsy. They have ruled out G syndrome, Zellweger syndrome, Prader-Willi syndrome and Pallister-Killian syndrome. Next, Clifford's blood will be tested for Smith-Lemli-Opitz syndrome. I do not feel that he has enough of the characteristics of this syndrome but we will follow through with the blood test.

We read *Exceptional Parent* religiously in hopes of finding a child similar to our son. The original prognosis was for a child with severe retardation and medical impairment, if Clifford survived at all. However, each of Clifford's impaired organs has shown remarkable improvement, and tests show his brain is processing speech. We now face a very uncertain future and would appreciate any helpful information.

B.C. & C.C., New York

Circle #186

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond,
Exceptional Parent
209 Harvard Street, Suite 303,
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

Now there's help for older children who have nighttime accidents.

A GUIDE TO

Pull-Ups®
GoodNites®
DISPOSABLE ABSORBENT UNDERPANTS

Circle #133

GoodNites® keep older children dry overnight.

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Bed-wetting is a common problem for older children.

GOODNITES Absorbent Underpants offer discreet, easy-to-use protection in two sizes to fit boys and girls 45-85 pounds.

You and your child are not alone. Between 5 and 15 percent of all older children experience night-time accidents. That's almost 3 million children.

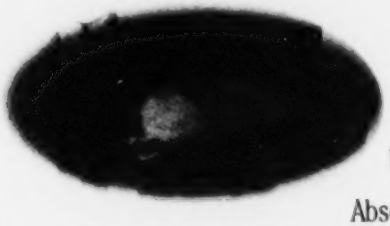
There are many causes of bed-wetting. Some are physical, and some are emotional. Since bed-wetting can be a sign of a more serious problem, the first step is to see your doctor or pediatrician. He or she can help you discover the cause and suggest the best treatment for your child's bed-wetting. Meanwhile, you can reduce the inconvenience of bed-wetting with protection from GOODNITES® Absorbent Underpants.

GoodNites® Absorbent Underpants help make your life a little easier.

With GOODNITES® Absorbent Underpants your child wakes confidently to a clean, dry bed. You and your child can sleep through the night so your day starts out easier without tension over bed-wetting or the hassle of extra laundry.

Your child will feel more confident with an active role to play.

A good way to help your child feel better about bed-wetting is to put him or her in charge



Allow your child to be responsible for storing his or her own GOODNITES Absorbent Underpants.

of GOODNITES® Absorbent Underpants. Your child can store, put on and dispose of GOODNITES Absorbent Underpants and let you know when the supply is low. This will make your child feel positive about taking responsibility and help eliminate the helpless, passive feeling that often accompanies bed-wetting.

Why kids like GoodNites® Absorbent Underpants.

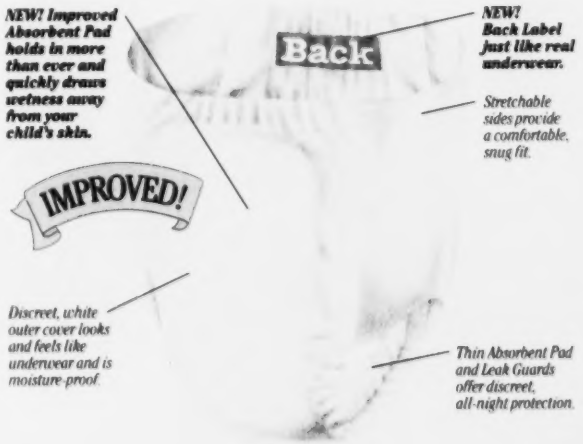
GOODNITES® Absorbent Underpants are specifically designed for larger children. They're plain white and go on and off like regular underwear. They even have a back label. GOODNITES Absorbent Underpants offer a trim, comfortable fit and are totally discreet, disappearing under pajamas to build your child's independence and confidence. Your child will not be embarrassed by crinkling plastic noises because GOODNITES Absorbent Underpants are quiet under clothing. Children who wear GOODNITES Absorbent Underpants feel better about themselves and that makes for better mornings for everyone.

How to make bed-wetting easier to control.

- **Watch what your child drinks**
  Limit liquids after dinner
  Drink water, not juice or soda
- Avoid soft drinks with caffeine
- Put child in charge of his or her own GoodNites® Absorbent Underpants
- Support and praise will help your child

GoodNites® Absorbent Underpants are comfortable, easy to use and provide all-night protection.

Try them and see why GOODNITES® mean good mornings.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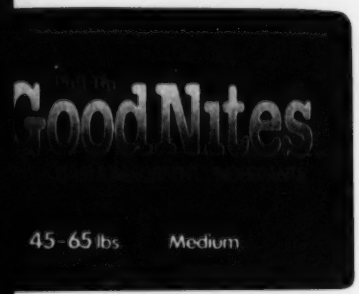

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GOODNITES® Questionnaire.

You can receive information and offers from GOODNITES® Absorbent Underpants by completing this form and mailing to us at the address below. The information you provide will help us learn more about the absorbent product needs of older children. The answers will be kept confidential and will only be used in aggregate to help us better meet the needs of children like yours. Thank you.

1. How old is the child using absorbent products? ____ Years
2. Is your child a boy or girl? Boy ____ Girl ____
3. How many NIGHTS in an average week would your child need an absorbent product? 0 ___ 1-2 ___ 3-4 ___ 5-7 ___
4. Does your child use absorbent products during the day? Yes ___ No ___
5. How many absorbent products would your child use in an average 24-hour period? ____
6. Have you purchased GOODNITES® Absorbent Underpants? Yes ___ No ___
7. How would you rate your satisfaction with GOODNITES Absorbent Underpants? Very satisfied ___ Neutral ___ Not very satisfied ___ Have not used GOODNITES Absorbent Underpants ___
8. Do you plan to buy GOODNITES Absorbent Underpants again? Yes ___ No ___ Have not used GOODNITES Absorbent Underpants ___
9. What other absorbent products does your child use? Check all that apply. Adult disposable incontinence products ___ Washable absorbent products ___ Disposable diapers ___ Disposable training pants ___ Other (please specify) _____

Mail to: GOODNITES® Survey
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El Paso, TX 88540-0029

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Name: _____

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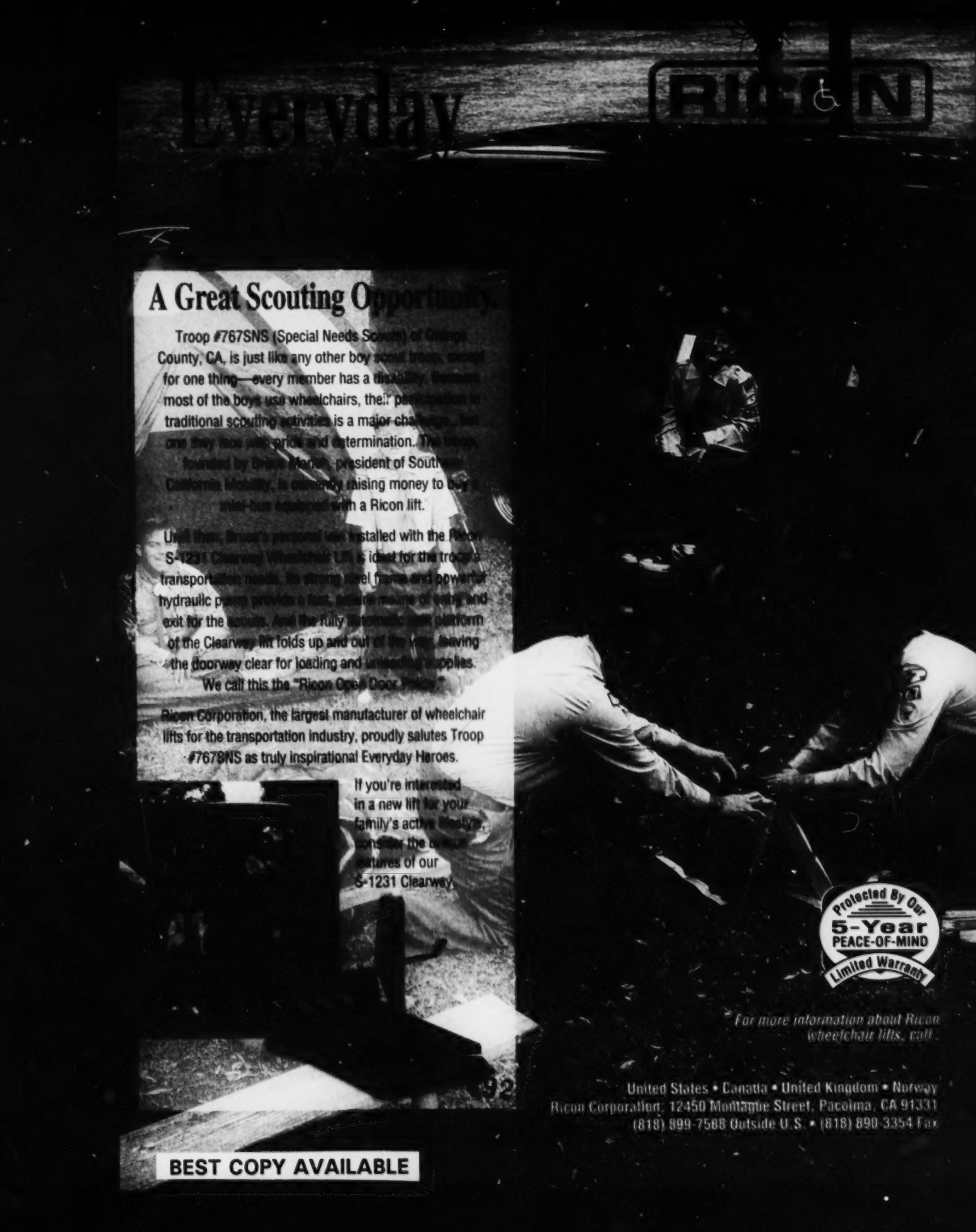
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A Great Scouting Opportunity.
Troop #767SNS (Special Needs Scouts) of Orange County, CA, is just like any other boy scout troop, except for one thing—every member has a disability. Because most of the boys use wheelchairs, their participation in traditional scouting activities is a major challenge, but one they face with pride and determination. The troop, founded by Bruce Meade, president of Southern California Mobility, is currently raising money to buy a mini-bus equipped with a Ricon lift.
Until then, Bruce's personal van installed with the Ricon S-1231 Clearway Wheelchair Lift is ideal for the troop's transportation needs. Its strong steel frame and powerful hydraulic pump provide a fast, safe and reliable means of entry and exit for the scouts. And the fully automatic lift platform of the Clearway lift folds up and out of the way, leaving the doorway clear for loading and unloading supplies.
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RESPOND

Therapeutic Recreation

E.W. (December, 1994) hopes to establish a community recreation program that includes children with disabilities. Specifically, he wanted to know how established programs of this type were operated and funded.

I suggest you contact the National Recreation & Park Association. Specifically, you should contact this special-interest section: National Therapeutic Recreation Society (NTRS), 2775 South Quincy St., Ste, 300, Arlington, VA 22206; (703) 820-4940, (703) 671-6772, fax.

The folks at NTRS should be able to advise you and put you in contact with existing programs in your area. Good luck!

D.V., Oregon

Early Myoclonic Encephalopathy

M.D. (October, 1993) wrote about her then six-month-old son, Austin, who has early myoclonic encephalopathy (EME), a rare seizure disorder. Austin was conceived while his parents were using the contraceptive sponge with Nonoxynol-9 spermicide. M.D. was hoping to find more information about EME and other parents with whom to correspond.

I originally wrote to you, enclosing my address and phone number, soon after your *Search* letter appeared in *Exceptional Parent.* As fate would have it, you called me the day of my son's funeral. That must have been horrible for you. But for some reason, I feel closer to you because of it and I would really like to get to know you. I know you also sent me a letter, but I was like a zombie for a few months after my son's death, and now I can't find your address.

Our lives have changed a lot in the last year. When Danny passed away in May, I was pregnant. Our son, Charlie, was born in September, 1994.

Last January, I landed a job as service coordinator for the Arizona Early Intervention Program. Several agencies wanted to hire me because of my "service coordinator" experience with Danny. At the time, I had no idea I was being a service coordinator; all I knew was that my son needed equipment, medical supplies, home nursing care and more. I found that I was more effective than our case manager in getting reimbursement approvals, so I did my own legwork.

At one point, I had approval for in-home nursing and desperately needed the help, but there were no state-contracted nursing registries that would provide a nurse for more than two hours at a stretch. So I recruited a different nurses' registry to contract with the state so I could have a nurse. I didn't know this was service coordination—I thought it was survival.

continued on page 38

KIDS MAKING TRACKS

They've **headed safaris** in their neighborhood park, and **pondered the panthers** and **pythons,** then **probed along the surface of Mars** in their trusty all-terrain vehicles. They've **recovered the last of the golden keys** while their computer proclaims them **heirs to the realm. Kid Power™ is for kids making tracks.** A child's tool, like a child's toy must be **durable** and **adaptable,** allowing them the **freedom** and **range** to **explore their environment creatively** and **independently. Kid Power™** is **tough** and **reliable** with a **unique styling** that **adjusts to your child's changing needs. Kid Power™ is easy to program,** with **precision controls, accessible battery boxes, controlled tracking, a rugged steel frame** and a host of options that allow kids to **assert their individuality** and **lifestyle.**

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493

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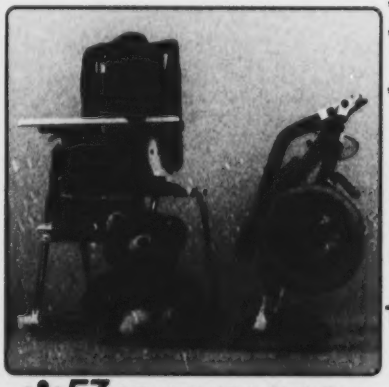

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Circle #98

continued from page 36

Another time, Danny needed respiratory treatments every two hours around the clock. I made it through 48 hours before I talked the insurance company into paying for in-home treatments and talked the respiratory therapists at the local hospital into doing the in-home work. Survival—not necessity—is the mother of invention. I'm glad I learned so much from Danny. Now, I am able to share my knowledge and abilities with other families.

How is Austin doing? And how are you holding up? I am definitely recovering from the loss of Danny and I would like very much to get to know you and your family. I hope you feel comfortable writing to me; and if you call, I promise no strangers will answer my phone this time.

B.S., Arizona

EDITOR'S NOTE: SEARCH letters often receive responses months, even years, after publication. Readers who have had SEARCH letters published at any time should make sure EXCEPTIONAL PARENT's editorial office (209 Harvard St., Ste. 303, Brookline, MA 02146) always has a current address to which we can send any responses we receive.

Persistent ATNR

T.W. (March 1995) has a 17-month-old son with cerebral palsy. Because of a very persistent asymmetrical tonic-neck reflex (ATNR), his right hand constantly digs into the side of his face. Someone has to hold his hand during play, therapy and feedings. T.W. wanted advice from others who have experienced this problem.

Over the years, I have taught several students whose abnormal reflexes caused them to hurt themselves or others. It is heart-wrenching to watch a child pull his own hair, gouge his ear or cheek, or bite through his lip when an abnormal reflex takes over. The child is caught in a vicious circle where the reflex causes pain which causes an increase in muscle tone, which strengthens the reflex, thus increasing the pain.

ATNR and bite reflex have caused the most trouble for my students. One of my students became a ball of nerves for fear that his out-of-control left hand would scratch his face, pull his hair or scratch his eye.

Here are four suggestions for dealing with ATNR:

First, consult with your therapists about positioning. Don't be afraid to try what may seem to be unusual options. Different things work for different kids, even for those with similar patterns of movement. You should aim to reduce overall tone (the level of tension in muscles at rest). What might seem like an uncomfortable position to you might be very soothing to your son if it frees him from his ATNR.

Second, try splinting. That's what worked for my student. His therapist and I used a small fabric knee immobilizer to keep his left elbow straight. He could choose to use the splint at any time—when he was playing, or doing artwork or schoolwork that excited him. The relief he felt at not having to worry about his hand translated into an overall reduction in tone. A word of caution, though—make sure all your son's caregivers understand the uses and limita-

495

tions of splints. Splinting should be used only to enable the child, never to restrict the child or to reduce the amount of supervision he receives.

Third, I have seen various barriers used to keep the offending hand away from the head. Perhaps you could extend a padded barrier from your son's head rest, or over his shoulder from the back of a positioning chair. When he goes into an ATNR, his hand will press against padding instead of his head.

Finally, your reaction to the ATNR is important. If you become anxious and view the problem as a struggle, your son will imitate you. Anxiety raises tone and increases the probability of reflex. Explain the situation matter-of-factly to your son in a way that he can understand, and assure him that you and his therapists will find a way to help him control the reflex and avoid pain. During activities, be calm and positive. Give him the support he needs and focus on the task at hand, not on the ATNR.

C.H., Florida

EDITOR'S NOTE: Seating and positioning expert Elaine Trefler, M.Ed., OTR reviewed this response for EXCEPTIONAL PARENT. In addition to the many good suggestions from C.H., Elaine notes also that some children with ATNR may find it useful to tuck an arm under a wheelchair tray to keep it out of the way.

Dandy-Walker Syndrome

C.K. (April 1995) have a five-year-old son with a variant of Dandy-Walker syndrome. Doctors say C.K. and her husband carry recessive genes for this disorder. Since C.K. and her husband would like to have a second child, they wanted to hear from families who carry a recessive gene for this condition.

Sometimes, children are diagnosed with a variant of Dandy-Walker syndrome but really have Joubert syndrome. In the past, it could be difficult to differentiate the two conditions, however, this is changing as more research is done.

Joubert syndrome is genetically transmitted, and a decision about having more children is always difficult. We had a healthy baby girl after our older daughter was born with Joubert syndrome. I firmly believe that the decision about another pregnancy depends on what each couple thinks they can handle. They need to be prepared for either possible outcome.

I am the founder of the Joubert Syndrome Parents-In-Touch Network (12348 Summer Meadow Rd., Rock, MI 49880; 906/359-4707). If you would like more information about Joubert syndrome or our organization , you can contact us.

M.V.D., Michigan

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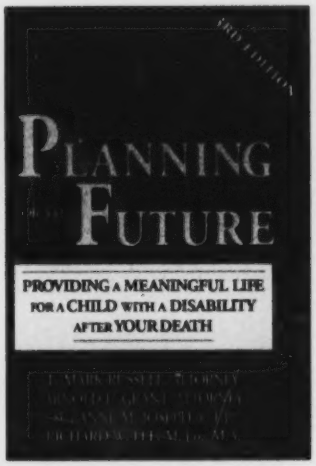

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—Sister Elaine Weber, O.S.F., Executive Director, St. John's Villa, Carrollton, Ohio

"Expert information on this very important often complicated topic. Very valuable for parents and professionals."

—Stanley D. Klein, Ph.D., Editor in Chief, *Exceptional Parent Magazine*

"Planning is this book's overriding feature—no matter what the disability or how small or large the income, if there is a well-considered and thoughtful plan...children with disabilities will have a greater chance of enjoying the best possible health and security. This book is a must purchase for all parents who have children with emotional, physical, or mental disabilities."

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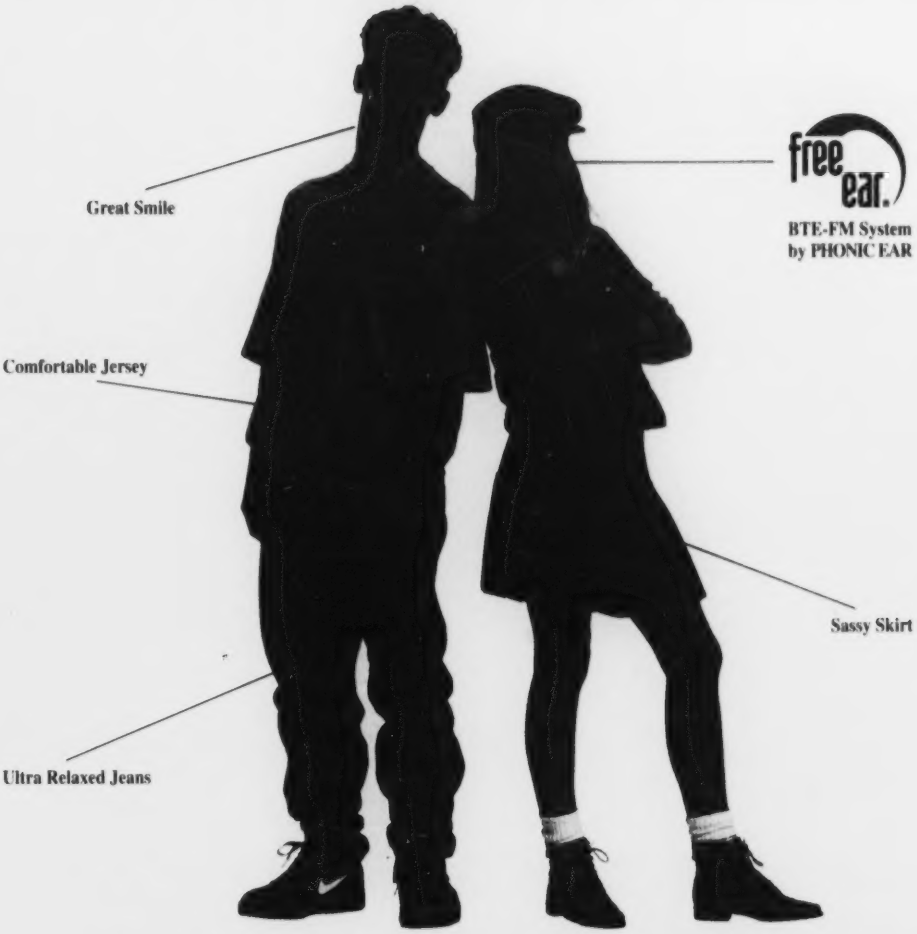

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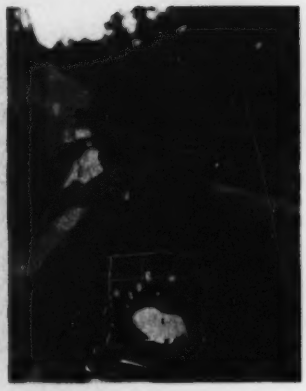
Circle #256

Familiar Faces

Coming through! Three-year-old Rachel Ahrens shoots down a slide at the indoor playground at McDonald's, one of her very favorite hang-outs. Rachel, who has low muscle tone, hip dysplasia and facial dysmorphia, is undiagnosed. She communicates using a combination of sign language, speech, an augmentative communication device, and, in this case, her broad smile. Rachel lives with her parents, David and Ginny, in Bemidji, Minnesota.



Christopher Metcalf, 4, sports the cap of his home team—the Colorado Rockies. An avid baseball fan, four-year-old Christopher lives with his parents and big sister, Larissa, in Littleton, Colorado. Christopher has a low-grade astrocytoma brain tumor, and, due to a stroke, has left-side weakness and developmental delays. He attends an integrated preschool.

Tiptoeing through the pages, **Kayla Felicia-Marie Allain** doesn't let anything keep her from her favorite pastime—reading. Kayla, 18 months, was born without arms but has found that her feet work just as well. Better known as "Sunshine," Kayla lives in New Orleans, Louisiana.

And now, coming down the track, in his third year of Soap Box Derby competition... it's **Jeffrey Stewart!** Jeffrey, 9, of Jamestown, New York races in one of four dual-controlled cars purchased by the Masonic Blue Lodge, Chautauqua District, for use in the Special Olympian Division of the annual competition. Jeffrey, who has autism, loves participating each year and wears his souvenir T-shirt and helmet with pride.

Young horseman Brian Crane is riding high on "Roz," his registered Shetland mare, led by 11-year-old brother, Mike. Brian, 4, has cerebral palsy, hydrocephalus and a seizure disorder. The family lives in Sheldon, Vermont.

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of* Exceptional Parent*? Send it to: Readers' Photos,* Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

500

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For more information please contact
Catherine M. Welch, MEd,
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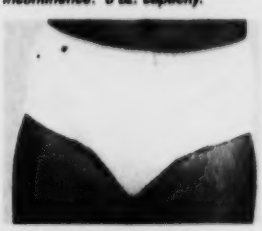

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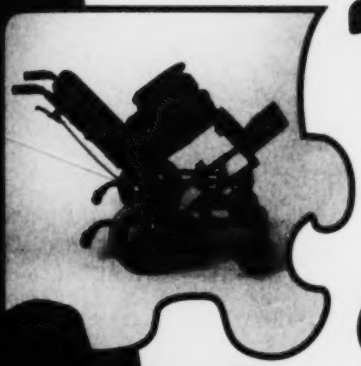

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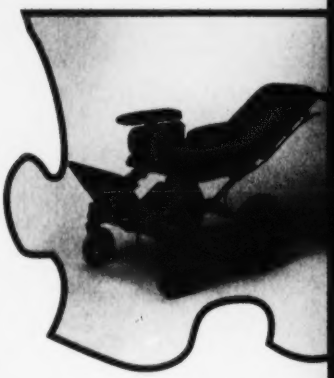

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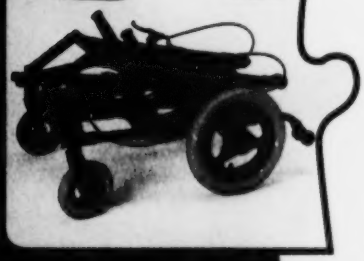

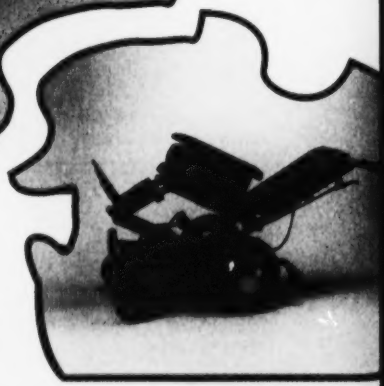

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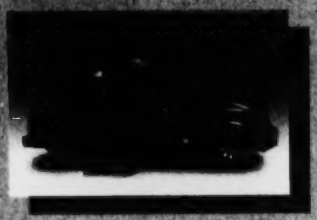

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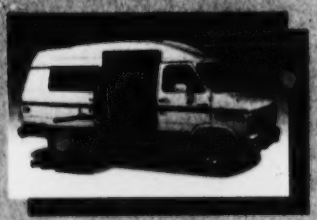

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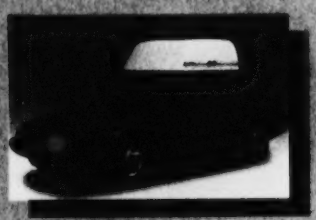

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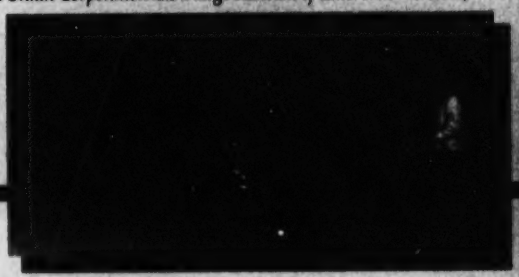

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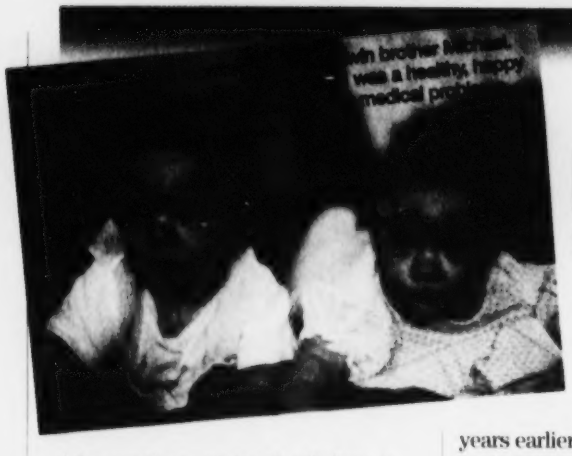

Fathers' Voices

Loving Sarah

by David L. Parsons

After we dropped Sarah off, I sat in the car and cried. Actually, I sobbed. All of the frustration, anxiety, fear and love went through my body in one spasm after another. I remembered all the sleepless nights, doctors, hospitals, special diets, vomit and diarrhea. Then there were all the words I could hardly spell—hyperammonemia, urea cycle deficiency, ornithine transcarbamylase.

But I also remembered all the tender moments with Sarah—her giggles and laughs, her teasing, her love and her courage.

After 20 years of living at home, Sarah was now enrolled in a residential school. I missed her already, and as tears poured down my face and old emotions swirled around me, a whole new set of fears jumped in—who would watch and protect her, check her diet, hold her hand, help her dress in the morning and kiss her good night?

On the familiar drive to pick Sarah up for a weekend visit home, I turn off the radio and roll down the windows on a beautiful September afternoon. I want to write about my life with Sarah, but how do I write about something that is as much a part of me as breathing? I'm still reflecting on our life together as I pull into the same parking lot where I sat crying five years earlier. I turn off the car, settle back and let the memories wash over me. I don't have to go looking for Sarah—I know I will hear her long before I see her…

Life with Sarah

Sarah has a deficiency of a liver enzyme called ornithine transcarbamylase (OTC) which is critical to protein metabolism. The condition is classified as an urea cycle disorder (see sidebar, page 50). By the time Sarah's condition was diagnosed, she had suffered irreparable brain damage.

Sarah, 13 months, enjoys a wagon ride. By the time her condition was accurately diagnosed, at 18 months, irreparable brain damage had occurred.

Life with Sarah is much what it must be like to be a Siamese twin. She is all-consuming; her moods affect my own. If Sarah tugs to the right, I have to follow; if I want to go to the left, I have to pull her along.

Small trips to the store can become major events. Sarah may get scared and scream hysterically, or she may decide she wants a piece of candy and have a full-blown tantrum—sitting in the middle of an aisle and screaming at the top of her lungs.

Because Sarah is hyperactive, playtime usually becomes a constant state of turmoil. In trying to relate to other kids, she pokes, hits and aggravates others. Her friendly personality, however, must somehow pull her through because most kids develop a real affection for her.

Sarah is one of the most loving people I know. She thrives on people, and plays hostess at most parties, introducing herself to everyone. In fact, she has a dynamic personality. You always know when Sarah is around.

Life with Sarah is full of emotions—often all mixed together at the same time—from love to hate, from panic to calm, and everything in between. This dichotomy of emotion is symbolized by my two greatest fears—the first, that Sarah will die, and the second, that she will outlive Pam and me.

A joint effort

No part of my life escapes the effects of Sarah—family life, social life, business life, marriage and sex life. It has been a joint effort, with my wife, Pam, taking the brunt of it and the rest of us pitching in. For the family, it has been a shared sacrifice. Vacations were nonexistent when Sarah lived with us; even little things like movies

continued on page 50

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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Braun has recently released a helpful booklet entitled "Guidelines". If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All sources for motor vehicle rebates are also listed in this comprehensive booklet. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

More About Urea Cycle Disorders

A urea cycle disorder is one of six genetic disorders causing an enzyme deficiency in the urea cycle. The urea cycle is the body's way of breaking down excess protein into urea, which is eliminated from the body with urine. The urea cycle requires different enzymes, but when one of these enzymes is missing, it creates a blockage in the cycle that results in the build-up of ammonia in the blood. The highly toxic excess ammonia (known as hyperammonia) reaches the brain through the blood where it may cause irreversible brain damage and/or death.

One in every 25,000 children is affected by a urea cycle disorder. Many physicians believe there are many more cases, but they are not properly diagnosed.

The effects of a urea cycle disorder usually do not appear until after the first 24 hours of life. At that point, the infant becomes lethargic and begins vomiting. Soon after, seizures, decreased muscle tone, respiratory distress and coma may occur. Death generally occurs if no immediate intervention is taken to decrease the ammonia level. Cases where symptoms appear at later ages may be caused by a partial (rather than total) enzyme deficiency.

Treatment, individualized for each child, generally consists of a low-protein diet and the use of medications which provide ammonia removal. Prompt treatment may prevent brain damage and/or death.

This information was provided by the National Urea Cycle Disorders Foundation, P.O. Box 32, Sayreville, NJ 08872, (800) 386-8233.

continued from page 48

were few and far between.

But I have watched my other kids grow up with a strong sense of moral and emotional strength. Living through crisis after crisis teaches priorities.

Our marriage has come close to the breaking point more than once. It was hard enough when Pam gave birth to twins—Sarah and her brother, Michael. But Sarah's disease was truly traumatic. She had lapsed into comas twice by the time she was 18 months old. She couldn't sleep and would thrash and cry all night long.

The doctors were brutal on Pam, telling us that Sarah's problems were the result of some sort of psychological mother-daughter syndrome (funny how they never thought it was a father-daughter syndrome). They ignored the fact that Sarah's twin brother was a happy, healthy baby. The doctors put Sarah in the hospital, told us to stay away and force fed her until she was comatose and paralyzed on her right side. Only then did the doctors decide maybe it wasn't psychological. The end result—besides an irreparable assault to Sarah's brain—was an emotional cauldron of guilt, betrayal, bitterness and hatred that Pam and I must dance around.

Constant stress

Romance and sex were something I saw only on soap operas. Pam and I had no time to be alone. In 18 years, we had only one vacation as a couple. A night at the movies or dinner alone

continued on page 52

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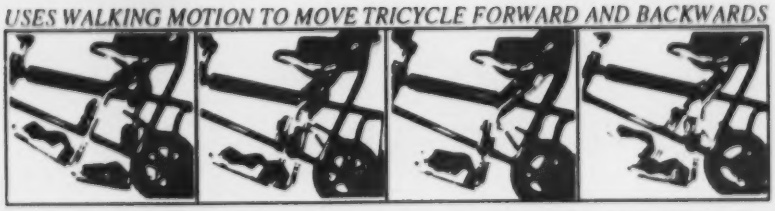

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Circle # 31

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continued from page 50

was a major event. Babysitters were hard to find and Sarah's grandparents couldn't handle her any better than the babysitters.

The stress was constant. When Sarah was healthy, she was in constant search of food. We had to watch her like hawks or she would sneak food and end up sick. When Sarah was sick, it required constant vigilance to make her healthy again. In her early years, she was a guinea pig for researchers. At the time of her diagnosis, she was only the fifth known case of OTC deficiency in the country, and the other four were dead. Needless to say there was no romance, no sanctuary for retreat, no quiet from the storm.

Our social life was limited. Even friendships were defined by Sarah. The people who could not deal with her soon disappeared from our lives.

Back at school

"Daddy! Daddy! Daddy!"

I look up to see Sarah running toward me, both arms straight out in front of her, trying to hug me from a block away. She is running, laughing, giggling and screaming with delight, all at the same time. She keeps her arms outstretched the whole way across the courtyard. I climb out of the car and try to keep from crying so she won't ask me, "Daddy, are you sad?"

She reaches me with a big hug. I pick her up and swing her around in the air, then set her down and give her a kiss. She puts her hands on the sides of my face, pulls me down and whispers in my ear, "It's not easy being the best, is it Dad?" That's her favorite question, and a routine with us.

"No, Sarah, it's not," I say.

"You're my friend, aren't you, Dad?"

"Yes, I'm your best friend."

"I love you, Daddy."

"I love you, too, Sarah."

Sarah, 24, shares a moment with David, her dad and "best friend."

And we get in the car and head for home. **EP**

David L. Parsons graduated from Yale University with a BA in English in 1968 and an MFES in environmental studies in 1971. He lives in Barrington, Illinois with his wife, Pamela, and children, Sarah and Michael, 26, Melissa, 22, and Sean, 13. Active in the real estate profession for 22 years, he is president of a land development company and a construction company.

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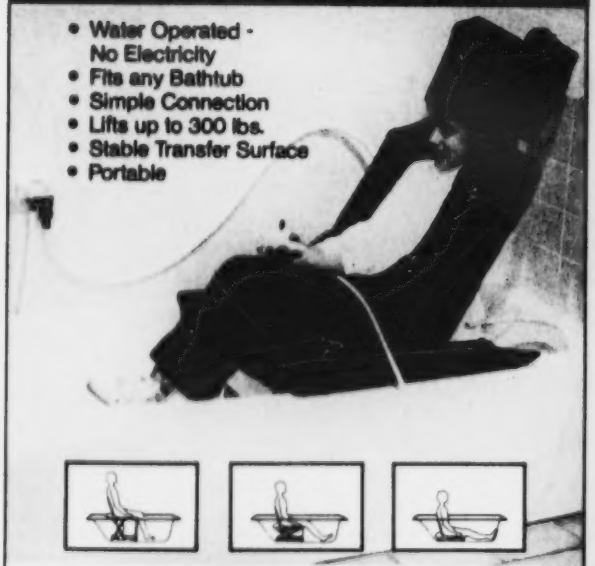

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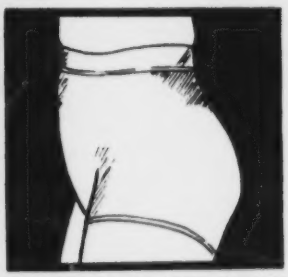

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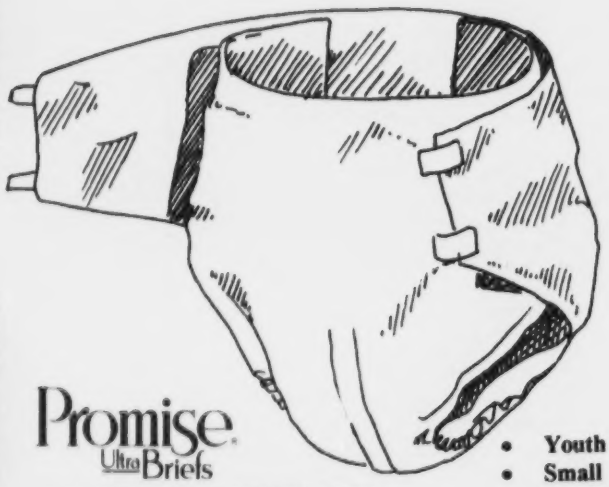

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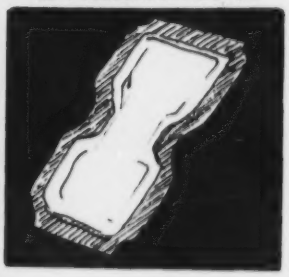

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Circle #249

RECREATION

UNIFIED SPORTS Gains Momentum At '95 World Games

by Michael Janes

The 1995 Special Olympics World Games will leave a legacy that stretches far beyond the usual remnants left behind at most athletic competitions.

That legacy will be comprised of the record number of individuals with mental retardation competing, the millions of spectators who witness the event on television and in person, and the number of sports and competitions being featured. Perhaps most significantly, these games will showcase the abundance of sports and recreation opportunities now available for individuals with mental retardation.

One of the most notable of these new opportunities is Special Olympics Unified Sports, a program that combines, on the same teams, athletes with and without mental retardation.

Why Unified Sports?

The aim of Special Olympics Unified Sports is to provide Special Olympics athletes the opportunity for meaningful training and competition with teammates who do not have disabilities. The careful selection of teammates who are similar in age and ability ensures that Unified Sports participants play important and valued roles on the team. The program provides a forum for positive social interaction among teammates that often leads to long-lasting friendships.

"What 'Games of Inclusion' really means is that more Special Olympics athletes than ever before are being accepted as individuals in every aspect of our program," said Dr. Tom Songster, director of sports and recreation at Special Olympics International (SOI). "The exciting part is watching them take their Unified Sports experiences into other areas of their lives, such as school, work and their communities. Sports is simply the vehicle."

PHOTOS COURTESY SPECIAL OLYMPICS UNIFIED SPORTS

Growth

First introduced at the 1991 International Special Olympics Summer Games in Minneapolis, Special Olympics Unified Sports began with just three sports and 100 athletes. Only four years later, 11 sports—including, for the first time, golf, sailing, basketball, tennis and the marathon—will feature Unified competition. More than 1,000 Unified athletes and partners will compete together, and the numbers continue to grow.

Unified Sports has been especially successful in schools, where teachers and administrators have struggled for years to find a way to bridge the gap between students without disabilities and their special education peers. George Smith, director of sports training and education at SOI, says Unified Sports is one answer, noting that the program "provides an opportunity for people to have a common ground, and what better common ground than sports?" According to Smith, virtually any sport can be successfully incorporated into a Unified program, including those traditionally thought of as "individual" sports.

In his 10 years at SOI, Smith, whose responsibilities include the worldwide implementation of Unified Sports, has seen the program expand into nearly 30 countries. "You can take any sport and it can be logically, thoughtfully and successfully unified," says Smith. "It's remarkable to see the Unified concept catch on so quickly overseas, since the whole idea of inclusion is a relatively new one in some regions outside the United States."

Goals

The goals of Special Olympics Unified Sports are:

• *Skill development:* Under the direction of qualified coaches, participants develop sports skills as well as prepare

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themselves for participation in other community sports programs.

• *Competition experiences:* Athletes benefit from physical and mental challenges through participation in a variety of competitions organized by Special Olympics or by community sports organizations.

• *Meaningful inclusion:* Unified Sports rules and guidelines on age and ability grouping help ensure that all athletes play an important, meaningful and valued role on the team.

• *Community-based participation:* Unified Sports programs have found valuable partners in community parks and recreation departments, schools, Boys and Girls Clubs of America and many other community sports organizations. These partnerships help further include athletes in their community.

• *Friendship and socialization:* The program provides a forum for positive social interaction between teammates and often leads to long-lasting friendships.

• *Transition and choice:* Unified Sports programs help schools meet the transition mandates of the Individuals with Disabilities Education Act (IDEA) as well as providing a choice for athletes in and out of Special Olympics. "If you're a high school kid whose abilities aren't quite good enough for the Junior Varsity or Varsity teams yet, a Unified league provides the perfect forum for honing those skills," says Smith. "This program is all about choice, both for Special Olympics athletes and non-Special Olympics athletes."

Recruiting Players

The recruitment of players is one of the most important aspects of Unified Sports. When promoting Unified Sports to potential participants, the goal is to recruit approximately equal numbers of athletes with and without mental retardation, of similar ages and with similar athletic abilities.

Like any Special Olympics competition, athletes must fit the following criteria for participation in Unified Sports: age eight years or older and having mental retardation (or learning or vocational difficulties due to cognitive delay). Because Special Olympics athletes are matched with teammates of similar abilities, the most appropriate Special Olympics athletes will usually have a relatively high level of athletic ability. Those who do not yet possess the requisite skill level will find more meaningful training and competition opportunities on a regular Special Olympics team.

Unified Sports "partners," or players without disabilities, generally describe themselves as "recreational level" or "beginner players." The program is not designed for individuals who are participating on a varsity or junior varsity team at the high school or college level, or those who have competed at that level in the recent past. Such players are encouraged to participate in Unified Sports as coaches and trainers.

Unified Sports has received ongoing support from sports organizations such as the Amateur Softball Association, Billiard and Bowling Institute of America, National Recreation and Parks Association, Soccer Industry Council of America and the United States Olympic Committee.

For more information on Special Olympics Unified Sports, contact Special Olympics International, Director of Unified Sports, 1325 G St. NW, Ste. 500, Washington, DC 20005, (202) 628-3630. **EP**

Michael Janes is the media relations coordinator of Special Olympics International.

Take Me Out to the Ballgame

The Lions, a Fairfax County, Virginia unified softball team.

My 24-year-old son, Matthew, has been playing in a softball league for nine years. Matthew, who has Down syndrome, does not hit the ball hard nor does he catch well, but he is good on ground balls, makes short throws accurately—if a little slowly—and delivers more strikes than balls when called upon to pitch. He understands the game and loves to play.

Special Olympics made it possible for Matthew to succeed at this complicated game. More specifically, Unified Sports enabled him to play with peers who do not have disabilities (known as "partners") in a traditional softball league format where each team has an equal number of Special Olympians and partners.

Matthew began playing unified softball in 1987 in Fairfax County, Virginia. It was rewarding to see people with disabilities and of varying proficiencies play in a big-time sport, complete with umpires, cheering spectators, score books, league standings and a final tournament that included individual trophies and a picnic.

Four teams make up the top-level division where some Special Olympians can play almost as well as their partners. Although Matthew is among the weaker players and could just as easily fit in the next lower division, he plays on one of these teams.

The second division consists of six teams. At this level, partners contribute more to the games to keep play flowing smoothly. They spend more time teaching and must moderate their own play to complement the Special Olympians.

The third division consists of four teams of athletes who need more assistance. Often extra strikes are allowed to enable a batter to become a base runner. Sometimes, a partner drops a ball so a runner can safely reach first base.

The fourth level has only two teams. Unlike the other divisions where partners—and occasionally Special Olympians—pitch, balls are hit from a tee.

Two years ago, Matthew moved into a local group home with three other young men and a counselor. His job, Special Olympic sports, social and religious activities, and his family are his main interests. In addition to softball, he swims, bowls and plays basketball and soccer.

Special Olympic sports, particularly softball, have contributed much to Matthew's well-being. Our softball players range in age from their teens to their 60s and it comforts his mother and me to believe it will be around for a long time. Who knows, Matthew may have a 60-year career. He might even become a power hitter someday.

—Cecil G. Goad
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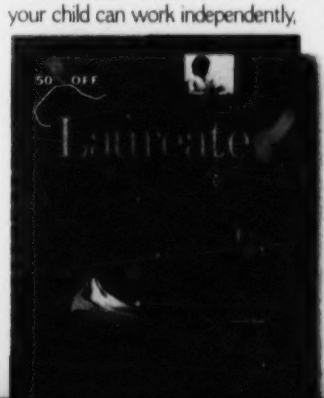

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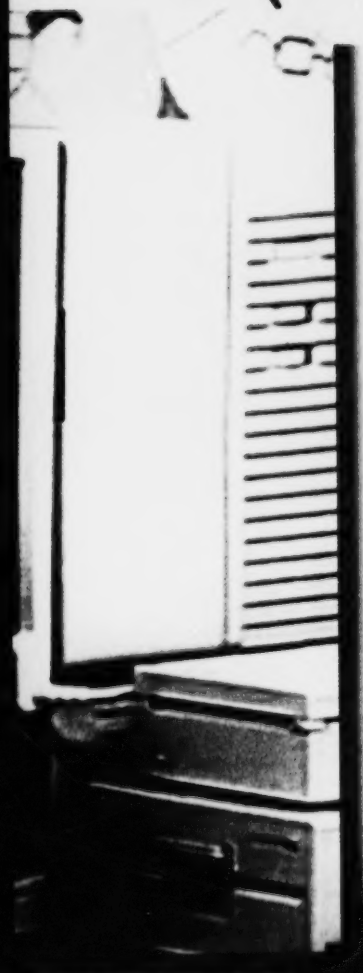

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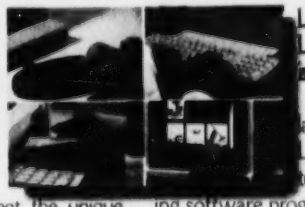
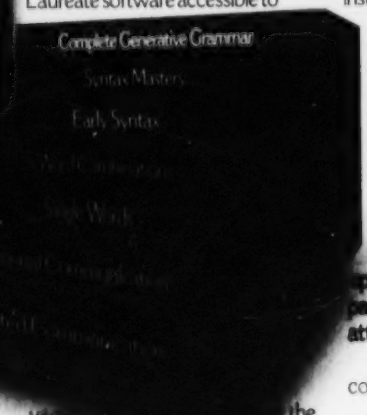
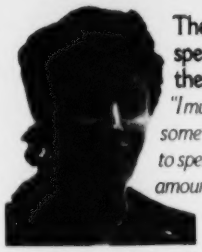




variety of the appropriate interface for your child: keyboard, game controller, Touch-Window, single switch, or mouse.



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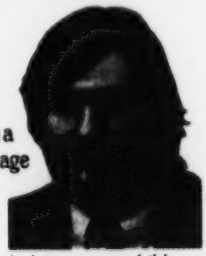

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Circle #45

Special Olympics State Chapters

Special Olympics participation is open to individuals who are over five years of age, and who have mental retardation or cognitive delays. Children may begin participating in Special Olympics competitive events at the age of eight. For more information on Special Olympics, contact Special Olympics International Headquarters, 1325 G St., NW, Ste. 500, Washington, DC 20005-4709, (202) 628-3630 (voice).

This spring and summer, Special Olympics state games will be conducted by all 50 state chapters. Prior to state games, athletes will compete in local or area competitions that will take place in more than 1,500 sites around the country. Athletes will compete in such sports as swimming, softball, running, equestrian events and bowling. For more information on Special Olympics events in your area, contact your state's chapter. (Phone numbers listed are for voice only.)

More than 450,000 athletes will take part in Special Olympics competitions this year; some will have the opportunity to represent Team USA at the 1995 Special Olympics World Summer Games in New Haven, Connecticut, July 1–9. For more information on the World Summer Games, contact 1995 Special Olympics World Summer Games, 195 Church St., 16th Fl., New Haven, CT 06510; (203) 498-7773, (203) 498-9618 (fax).

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Berkshire Meadows –

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Young bodies float in a broad expanse of bathtub warm water, supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex, laughter at splashes and water-antics, shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

For the boy in our picture above, the intense relaxation of the Hubbard Tank helps to maintain his range of movement. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more co-ordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young woman in the therapeutic pool also enjoys a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a moveable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the youngsters, when in the pool, to move in ways in which otherwise they cannot: when in the water they might walk independently, or might acquire real movement instead of spasticity. Here, in the supportive, liquid warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced, and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multifaceted program at Berkshire Meadows, a private, non-profit residential school for children and adolescents who are severely developmentally delayed and may be multiply disabled. Our program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of precognitive, cognitive, pre-vocational and independent living skills. We have an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.

For further information, please contact: Gail Charpentier, Executive Director, Berkshire Meadows, 249 North Plain Road, Housatonic, MA 01236 (413) 528-2523

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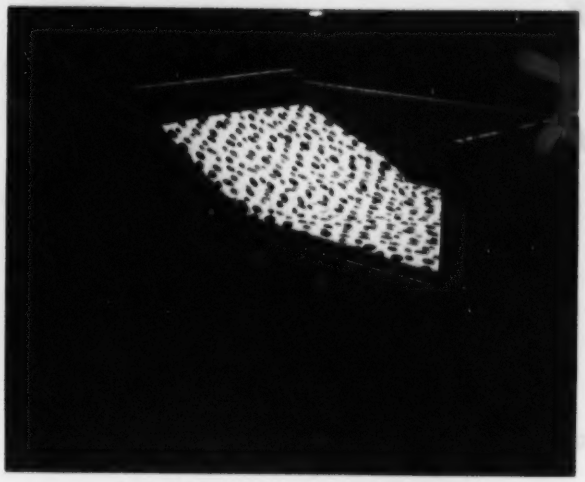

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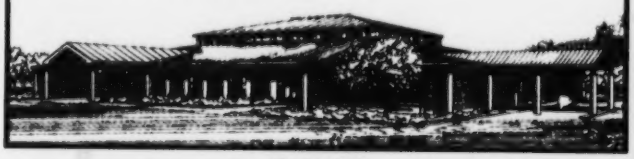

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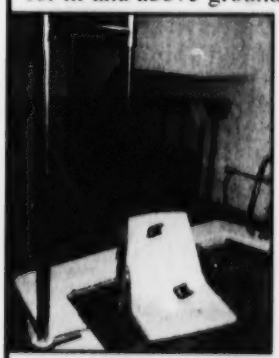

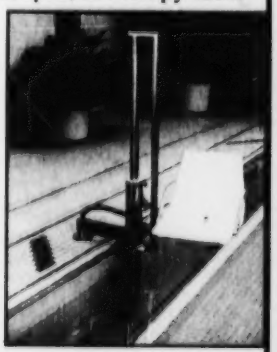

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Circle #230

Focus on Fitness

by Naomi Angoff Chedd

When I watch the Boston Marathon every April, I am moved beyond words as the first racers cross the finish line in their wheelchairs. I am still overcome as the final chair rolls in many hours later. The runners, of course, are first-rate athletes, but Jean Driscoll, record-setter and four-time Boston winner in the wheelchair division, is my true hero.

This year was the first time that my daughter watched the race from *her* wheelchair. So my interest was even greater, my emotions more easily ignited. Kinsey is quadriplegic and at age four, she is not yet thinking about training for a marathon. But whatever the future holds for Kinsey, it is my fervent hope that she will have access to and enjoy a variety of sports. Equally important, I hope she will reach a reasonable level of fitness. But even at age four, she has already come up against many barriers—physical, psychological and social—that no physician, teacher or therapist has sufficiently addressed.

Sports and fitness are not always about competition. In fact, the great majority of people, both with and without disabilities, do not race in marathons or compete in championships; they simply want to get a decent workout on a regular basis and have some fun.

Are children and young adults with disabilities getting adequate opportunities for fitness? Or will they lead sedentary lives, with a greater incidence of weight problems, hypertension, high cholesterol and heart disease? If we don't address physical fitness with our children, specifically cardiovascular fitness, such problems may be inevitable.

Fitness versus recreation

For children with physical disabilities, opportunities for sports and recreation are better and more abundant than ever. A growing number of ski areas have programs for children with special needs and offer sitski and monoski instruction. Equestrian programs for riders with disabilities are available in many states. And national organizations and community-based programs for wheelchair sports—everything from tennis to rugby—are on the increase. These efforts should be applauded, not to mention used and enjoyed to the hilt. However, not every sport provides the cardiovascular workout necessary for long-term health benefits.

Fitness is a major concern for many clinicians, including Karen Pape, M.D., a neonatalogist and neuropsychologist at the McGee Clinic in Toronto, Canada. She believes health care professionals need to address the topic with their patients with disabilities—as they do with all other patients. "If you diagnose a child with diabetes and simply prescribe insulin, you would be remiss, even liable. You need to provide complete nutritional, exercise and lifestyle guidelines," she says.

"We should be training children with disabilities like long-distance runners, not sprinters. That is, they need high repetition of cardiovascular exercises and not necessarily a lot of weight training. Think about how world-class athletes train, then adapt the program for kids with disabilities."

Naomi Chedd and daughter Kinsey, 4, participate in a weekly swim program sponsored by Massachusetts Easter Seal Society.

PHOTOS COURTESY MASSACHUSETTS EASTER SEAL SOCIETY. PHOTOS BY: JET COMMERCIAL PHOTOGRAPHERS

"The more severe the physical disability, the more you need to look to the water for the solution," advises Dr. Pape. Swimming and water exercise get the heart pumping; increase coordination, endurance and range of motion (of limbs) and can often reduce spasticity. Most important, it's fun. With regular exercise, grades, attitude and appearance may improve, and attention span can increase. Dr. Pape adds, "No matter what the disability, you can increase the level of fitness."

Dick Crisafulli, director of recreation at the Massachusetts Hospital School in Canton, Massachusetts, believes that the greatest challenges come in adapting programs because each child and each disability are so different. He also says that skill development often takes a lot longer for kids with disabilities. What an able-bodied child can learn in a few classes may take a child with a disability 20 classes. "You need to have time, patience and commitment, but success does come," Crisafulli says. "Take the kids to a ballgame, to the ballet, to tournaments. Get them to *ask* to participate. You need to work with them on a psychologi-

continued on page 64

DISABLED CHILDREN'S RELIEF FUND

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REHABILITATIVE SERVICES: Individual disabled children are eligible for rehabilitative service grants. This program is designed to provide rehabilitation services for disabled children, including but not limited to, surgery, physical therapy, and related health improvement services. This list is not all-encompassing of fundable rehabilitative services; it is provided for illustration purposes only.

INSTITUTIONAL GRANTS: Hospitals, rehabilitation centers, and nonprofit organizations that serve disabled children are eligible for institutional grants. Institutional applicants may request funds for assistive devices, rehabilitation services, or arts and humanities projects for **two or more children** (Institutions interested in a grant for only one (1) child should use the assistive devices or rehabilitative services grant applications). Applicants requesting funds for arts and humanities projects are encouraged to design creative programs. There are no restrictions on the program activities of this component, except that the activities must focus on encouraging and assisting disabled children in the arts and humanities. This program is designed to stimulate creative efforts, with preference for projects developed by children with disabilities.

For an application or more information call or write:
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Circle #254

continued from page 63

cal and physical level. They need to think, 'I bet I can learn to play tennis.'"

Another physical education instructor comments, "Kids with disabilities need to tell their coaches, 'Hey, I don't want to be the scorekeeper; I want to play.' Somebody needs to help them—and the rest of us—develop the right attitude."

More training and support needed

Paul Gorman of the National Center for Sports for the Disabled in Boston hopes his new organization, still in development, will serve as a regional model and resource that will provide fitness opportunities for people with disabilities, and training and support for professionals. The center will work with health care providers, teachers, therapists and parents to ensure that people with disabilities get equal access to sports and fitness programs.

Gorman wants to show the community how programs can be integrated and how they can work. He points out that many schools are trying hard to include kids with disabilities in their physical education programs but they need more education and support.

Photo courtesy Massachusetts Hospital School, Canton, MA.

What can parents do?

I can hear the moans and groans from coast to coast: "I'm a mother, not an athletic director..." "My daughter already gets physical therapy twice a week..." "With all the medical and therapy appointments, don't I have enough to do?"

The reality is that parents have to take charge of their children's fitness. The good news is that there are many committed professionals who are willing to help. Here are a few suggestions:

• *Enlist the help of your pediatrician.* Many physicians don't even bring up the subject of fitness. They may never think of it, or knowing that parents of children with disabilities are already overworked and overtired, may believe they would not be interested. Let your child's doctor know that fitness is a priority. Ask for nutritional guidelines, too.

• *Devise a plan with your PT and OT.* They are the ones who know your child's physical capabilities best and can identify ways for the child to work toward an optimum level of fitness.

continued on page 66

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You can see the delight in Rebecca's eyes. When she answers a math question in her fifth-grade classroom...or creates art to hang in the halls of her school..or sings with the choir in a program at City Hall..she enjoys discovering her world.

Rebecca was eight when she arrived at Heartspring. She was unable to express herself... uncontrollable in her home...and uncooperative with her teachers. She was making no progress in a regular classroom, but her parents were reluctant to see their daughter assigned to one-to-one programming. Today, thanks to a program designed to meet this special child's needs, Rebecca is a happier little girl.

At Heartspring, a caring team of specialists take the time to discover each child. Together with the parents, they develop an individual education plan (IEP) to fit the child's needs.

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Circle #3

continued from page 64

• *Work closely with your child's physical education (PE) instructor.* And get your PT and OT involved, too. It might not take much to give your child more opportunities for fitness—a few strategies for including your child in an activity or ideas for adapting a piece of equipment. Most PE teachers do not have the time or training to individualize programs for every child with special needs, but as one instructor told me, "I'll try anything you suggest."

• *Identify community programs and classes.* Swimming, self-defense, yoga, aerobics and gymnastics classes are often available at "Y's" and fitness centers. Many have not included children with disabilities only because they've never been asked. Others may need help in tailoring the class to your child's needs. Your PT and OT can advise you on appropriate activities and the equipment and support your child might need for a specific activity.

• *Get wet!* If at all possible, get your child into the water and moving as often as you can. Approach your local "Y" or community pool about starting a program for swimmers with disabilities. A number of available devices can make rigorous aquatic exercise possible. An aquajogger, which is a vest that keeps a person buoyant and vertical, can allow a child to "jog" in the water.

• *Be a good role model.* If exercise is a regular part of your routine, your kids will want to join in. Try to participate in an activity you really enjoy; enthusiasm and motivation are contagious. Summer is a good time to begin a cardiovascular fitness program. When school begins in the fall, the school PE instructor can work with your child to maintain a higher level of fitness, rather than starting from scratch. And remember—you can write physical education goals into your child's IEP. **EP**

Naomi Angoff Chedd is a member of EXCEPTIONAL PARENT'S *editorial staff.*

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Circle #1

Role Models

Mary Verdi-Fletcher

Born with the spirit of a dancer

Five-year-old Mary (left) enjoys her first "dance lesson" with her mom Nancy, cousin Rita and brother Brian.

Mary Verdi-Fletcher, 39, is principal dancer and founder of the Cleveland Ballet's Dancing Wheels, a company established in 1980 for people with disabilities to explore the world of dance. A second Dancing Wheels company, called Danceability, has been established in Atlanta; a third is being developed with Ben Vereen's performing arts school in Chicago. Verdi-Fletcher is also president of Professional Flair, a nonprofit arts/disability organization. The Cleveland native and Lakeland Community College graduate has spina bifida. She lives with her husband, Bob, in a Cleveland suburb. The following was adapted from a recent interview between Verdi-Fletcher and Michele San Filippo, an EXCEPTIONAL PARENT *intern.*

Someone once said to me that the arts are a vocation that chooses you; you don't choose them. I believe I was born with the spirit of a dancer and it was through fate I was able to pursue it.

I started dancing at the age of three. I would groove to the radio all the time. I remember doing the Mexican hat dance at age five when the nuns of Our Lady of Lourdes Shrine in Cleveland asked me to dance. Once a month, I would break my braces while dancing; then I broke my leg three times because I got new braces that were too strong. I even broke my wheelchair a few times.

Young Mary meets Pope Paul VI in 1965 with her grandmother, Marghrita Baruzzi (far left), and mother Nancy.

In 1975, I became involved in dance on a social level and began going out dancing in groups. I liked popular dances, mostly freestyle and disco, but also enjoyed ballroom.

My mother, a professional dancer for 15 years, inspired me to dance. My dad, a General Electric quality-control technician, played saxophone and clarinet part-time until about 12 years ago. Hearing my parents' stories of their vaudeville days during the war, really made me interested in dance. My parents met on the stage while Mom danced and Dad played "Moonlight Serenade" in the orchestra pit. I also enjoyed watching movies with Gene Kelly, or Fred Astaire and Ginger Rogers.

Sheltered childhood

When I was born, little was known about spina bifida, and there were no parent groups. My parents were told I wouldn't live past the age of three and if I did live that long, I would be a "vegetable." The doctors encouraged them to put me in a home. Luckily, they didn't.

In 1950, babies with spina bifida were sometimes just left to die; I was born in 1955, after doctors started keeping babies alive and trying to find ways to help them. The doctors didn't know what to expect. I had one of the worst cases of spina bifida they had ever seen.

My parents were afraid to let me be independent. They were very protective and didn't allow me to go out with friends. They did it out of love and fear, but their protectiveness prevented me from developing social skills like other youngsters. My parents were big proponents of education, however, and wanted to give me the best schooling possible.

My mom took me to Villa Angela Academy, a Catholic, all-girls high school, every day. She would stay to carry me upstairs so I could attend class with able-bodied kids. She ended up getting an audio-visual job at the school just to be around for me.

For two years I attended this inaccessible 90-year-old school with many stairs and a rickety elevator. In my sophomore year, a new one-level building was built; I could get around a *lot* better. I really had a good time there studying voice and performing in all the theater produc-

continued on page 70

525

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Circle # 74

continued from page 68

tions. A few years ago, I was chosen by the Sisters to be in the Villa Angela Academy Hall of Fame.

Love and respect

My relationship with my parents was like a wave. There were times when I loved them dearly; but other times, I felt resentful. I was resentful for a while because I wasn't allowed to go out and be with other kids. I resented that they didn't think I would ever be married because of my disability. But, I got over it and understood why they felt the way they did. No matter what, I have always had love and respect for them.

My parents dealt with my disability the best way they knew how. I grew up with my older brother and cousins, which was very positive because my parents wanted me to be seen as their equal. Some of what my parents did was very helpful, because I grew up among able-bodied peers.

My parents always prayed for a miracle because that's what you did back then. I think the fact that I am here today is a miracle, given my 10 major surgeries growing up and three recent ones due to kidney problems.

Becoming independent

When I was in my mid-twenties I decided to pursue the things I wanted in life. A friend told me, "You have to learn not to take 'no' for an answer" and "For every door that closes, another one opens."

I didn't have many boyfriends back then because of my parents' protectiveness. If your mom is pushing you in

continued on page 72

Nancy Verdi (left) inspired daughter Mary to dance. This 1937 photo shows Nancy and twin sister Rena during their vaudeville days.

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There are five programs for women (from semi-independent to supportive) including one specifically designed for mature women. **A new community-based program for men has been added.** The program offers training in home care and maintenance, budgeting, household management, and participation in an established vocational program.

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For Information Call

(717) 297-2185

or write: Martha Lloyd Community Services
190 West Main St., Troy, PA 16947

The Dancing Wheels company includes performers with and without disabilities. (From left) Barbara Allegra Verlezza, Mark Tomasic, Sabatino Verlezza and Mary Verdi-Fletcher.

PHOTO: AL PUCHS

continued from page 70

your wheelchair, you won't have many guys coming up to you. Once I decided to become independent, I learned to drive a car and got a job. Within two years, I had tripled my salary and found someone at work I could room with. It was a major shock to my parents because they always expected me to live at home.

When I first told my parents I was moving out, they told me never to come home again. They hoped that would somehow keep me there. My response: "I need to leave, and I hope you will support me if I don't do well because I'm not sure how I will manage."

At that point I asked myself, "When I am 40 or 50, am I going to look back on my life and say, 'I should have done this or that?'" I'd much rather take the risk and hope things work out for the best.

Realizing the dream

Once I started to pursue a career in dance, it just happened. I knew I loved dancing and my dancing gave both able-bodied people and people with disabilities a different view of disabilities. Dance was still an art form that had not yet been explored by the disability community.

In 1980, I began getting paid as a Dancing Wheels performer. I danced part-time for many years while working full-time as development director of a non-profit organization serving people with disabilities.

In 1989, I decided to pursue dance full-time. I didn't know any professional dancers who had a disability, but I figured why not?

At first, people didn't believe I was a dancer, but when they saw me dance, they believed. Then, they questioned

continued on page 74

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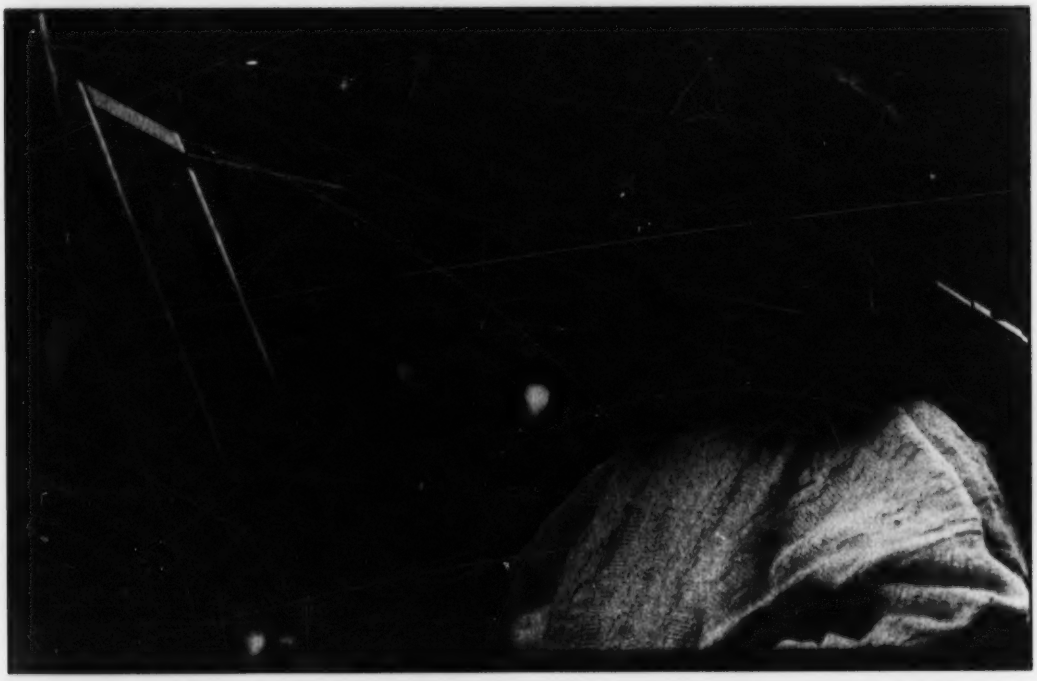

The Joy of Independence

Spring Time by Amy Neubauer

The joy of self-expression shines every day for students at Crotched Mountain Rehabilitation Center. Just 50 miles from Boston, surrounded by New England villages and towns, freedom and independence are celebrated with every graduating class. Throughout our progressive 60-year tradition, students have been realizing their dreams and achieving success.

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To find out more about the compassionate and caring services we provide for special children throughout the world, please call Debra Flanders in Admissions at 603-547-3311, ext. 235.

CROTCHED MOUNTAIN

A subsidiary of the Crotched Mountain Foundation

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internet: info@cmf.org fax 603-547-3233

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Circle #73

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whether Dancing Wheels was just "dance therapy" because some of us had disabilities.

Eventually the public started to accept us. The more they saw, the more they wanted to see and the more dances they saw, the bigger the productions they wanted to see. People now stop me on the street and say, "You're the dancer, aren't you?"

Many people think of dance in terms of only using our legs, when dance is actually an expression. It's an expression that *conveys* emotion. Dance comes from within, meaning it can be done in many different ways. This is the approach of dance today, but years ago it wasn't. If you couldn't use your legs, you couldn't be a dancer.

We use very high-tech lightweight wheelchairs, the Action line from Invacare. I use three different chairs, each of which responds very differently. My first chair was 55 pounds; these new chairs are under 20. With the flick of a finger, I can make the chair go in a complete circle and glide across the floor.

My mission is twofold. First, Dancing Wheels opens the eyes of able-bodied children to see the possibilities and similarities—rather than the differences—in all of us. And, second, the dance itself inspires children and adults with disabilities to feel a change within themselves. It creates self-esteem, dignity and an inner beauty that often does not come out. I see a transition in people as they take dancing classes. I see a change in the way they move and the way they feel about themselves; they exude confidence they didn't have before. I've seen it change people time and time again. **EP**

Verdi-Fletcher is collaborating with Ben Vereen to expand Dancing Wheels.

Haverich Ortho-Sport, Inc.
67 Emerald Street
Keene, NH 03431 (603) 358-0438

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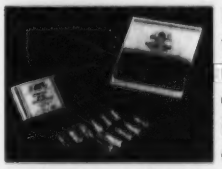

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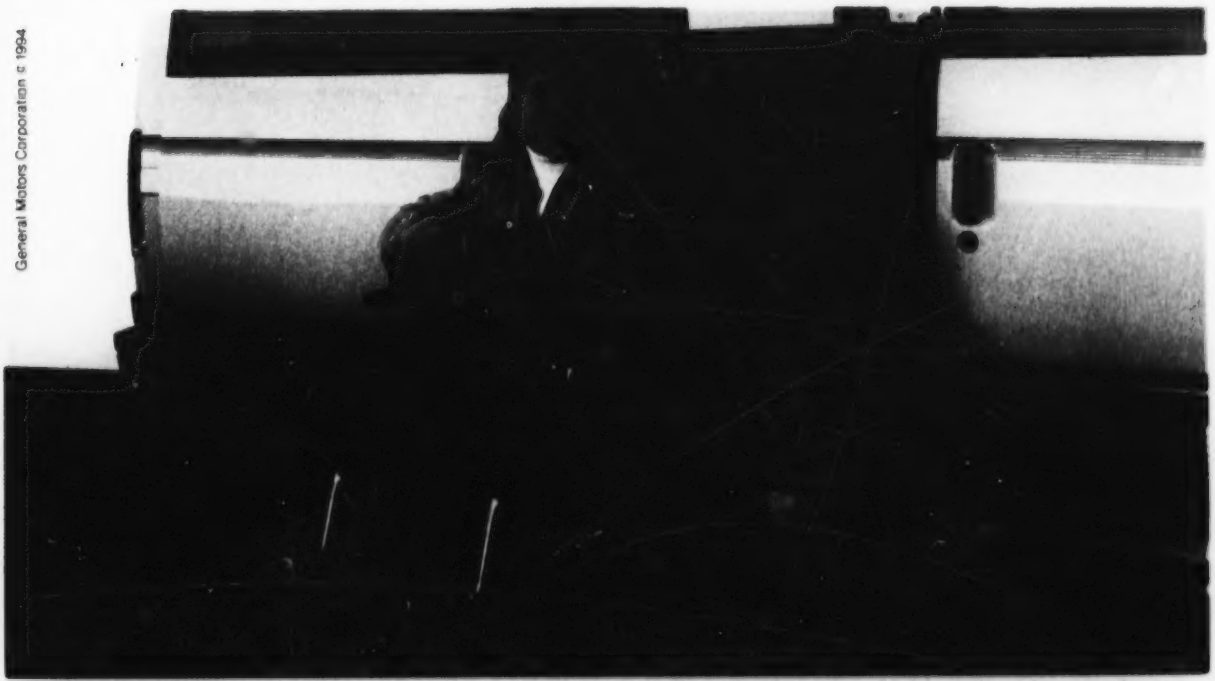

An active honor roll student, Tammie Groth doesn't believe in obstacles. Neither does her mother, Connie, one of the many General Motors employees whose own lives are affected by physical disability. It's their valuable insights that help make the GM Mobility Program work. Transportation means independence. That's something the people at General Motors know from their own experience.

Call the GM Mobility Assistance Center. We'll give you: • The names of local companies that provide driver assessment services, adaptive driving devices and vehicle modifications. • An informative videotape, "On the Move Again." • Suggestions for the General Motors cars and trucks that might work best for you. Then, if you buy or lease a new GM vehicle, we'll reimburse you up to $1000 toward the cost of adapting it or reinstalling your own adaptive equipment. Call 1-800-323-9935 (TDD users: 1-800-TDD-9935), or contact your Chevrolet, Pontiac, Oldsmobile, Buick, Cadillac or GMC Truck dealer to find out more.

Recreation Resources

This directory includes national groups and organizations that can serve as resources for recreational and sports activities for children and young adults with disabilities. Groups listed in the "General" category can provide information and referrals for a number of different recreational activities and sports.

A description of services provided by individual groups follows each listing. Numbers correspond to items listed in the Key to Services. If a group serves a specific age range and/or disability, the age range and disabilities are given in parentheses at the end of its listing. If not otherwise indicated, the group serves people of all ages and/or with all disabilities.

This symbol (✉) indicates an Internet e-mail address. Unless otherwise indicated, telephone numbers are for voice only.

Key to Services

1. ORGANIZES NATIONAL COMPETITIONS
2. ORGANIZES LOCAL COMPETITIONS
3. TRAINS LEADERS, SUCH AS COACHES AND PARENTS
4. PROVIDES INFORMATION (I.E., VIDEOS, PUBLICATIONS)
5. OFFERS FREE LOANER EQUIPMENT TO PARTICIPATE IN PROGRAM (I.E., RACING WHEELCHAIRS)
6. OFFERS EQUIPMENT USE FOR A FEE
7. PROVIDES FINANCIAL AID

General

American Athletic Association of the Deaf
3607 Washington Blvd, Ste 4
Ogden, UT 84403-1737
(801) 393-8710 (voice)
(801) 393-7916 (TTY)
(801) 393-2263 (fax)
1,2,3,4,5,7 (deaf, hearing impairments)

Boy Scouts of America
Scouting for the Handicapped Service
1325 W Walnut Hill Ln
Irving, TX 75038
(214) 580-2000
(214) 580-2502 (fax)
1,2,3,4,5

Photo by Mary Carol Peterson, Sports 'N Spokes/Paralyzed Veterans of America, Phoenix, AZ

Canadian Wheelchair Sports Association
1600 James Naismith Dr
Gloucester, ON CAN K1B 5N4
(613) 748-5685
(613) 748-5722 (fax)
1 (6–60 years; wheelchair users)

Disabled Sports USA
451 Hungerford Dr, Ste 100
Rockville, MD 20850
(301) 217-0960
(301) 217-0968 (fax)
1,2,3,4,5,6 (mobility impairments, visual impairments)

Girl Scouts of the USA
Services for Girls with Disabilities
420 5th Ave
New York, NY 10018
(212) 852-8000
(212) 852-6515 (fax)
Different services offered through local chapters (5–17 years)

National Sports Center for the Disabled
PO Box 36
Winter Park, CO 80482
(970) 726-5514
(970) 892-5823 (fax)
1,2,3,4,6,7

Perfect Fit (4-H programs)
Purdue University; Cooperative Extension Service
1161 Agricultural Administration Bldg
W Lafayette, IN 47907-1161
(317) 494-8423
(317) 496-1152 (fax)
3,4 (10–19 years)

Wheelchair Sports, USA/National Wheelchair Athletic Association
3595 E Fountain Blvd, Ste L1
Colorado Springs, CO 80910
(719) 574-1150
(719) 574-9840 (fax)
✉ Wheelchair@aol.com
1,2,3,4 (wheelchair users)

US Association of Blind Athletes
33 N Institute St
Colorado Springs, CO 80903
(719) 630-0422
(719) 630-0616 (fax)
1,2,3,4,5,6,7 (blind, visual impairments)

US Cerebral Palsy Athletic Association
3810 W Northwest Hwy, Ste 205
Dallas, TX 75220
(214) 351-1510
(214) 352-1744 (fax)
1,2,3,4 (6 and older; cerebral palsy, traumatic head injuries, stroke survivors)

Photo courtesy United Cerebral Palsy Athletic Association, Dallas, TX.

Aquatics

Dwarf Athletic Association of America
c/o Sarah Beth Ely
12101 S Mulino Rd
Canby, OR 97013
(205) 743-3424
✉ Swimmer79@aol.com
1,2 (Persons of short stature—4'10" or less adult height—due to achondrodysplasia or similar medical conditions)

US Cerebral Palsy Athletic Association
See listing under "General"

US Wheelchair Swimming
c/o Larry Quintilani
229 Miller St
Middleboro, MA 02346
(508) 946-1964
(508) 946-4737 (fax)
✉ ltquinn@aol.com
1,2,3,4 (7 and older; mobility impairments)

Archery

Wheelchair Archery USA
c/o Lynn Rourke
3595 E Fountain Blvd, Ste L
Colorado Springs, CO 80910
(719) 574-1150
1,2,3,4

Basketball

National Wheelchair Basketball Association
c/o David Kiley
Casa Colina Centers for Rehabilitation
2850 N Garey Ave
Pomona, CA 91769-6001
(606) 257-1623
(606) 258-1090 (fax)
1,2,3 (7–65 years; physical disabilities)

National Wheelchair Basketball Association Youth Division
c/o Bob Szyman, Commissioner
St. Louis Wheelchair Athletic Association
6420 Clayton Rd
St. Louis, MO 63117
(314) 768-5325
(314) 768-5316 (fax)
1,2,4 (high school students, 21 and under; physical disabilities)

USA Deaf Basketball
c/o Bennie Maucere
3964 Murietta Ave
Sherman Oaks, CA 91423
(818) 789-9573 (TTY)
(818) 789-2087 (fax)
✉ Jamesr111@aol.com
1,2,3; Offers youth basketball camp

Boccia

US Cerebral Palsy Athletic Association
See listing under "General"

Bowling

American Blind Bowling Association
c/o Ron Beverly, Editor/PR
67 Barne Ave
Buffalo, NY 14215
(716) 836-1472
1,2,4,6 (18-80 years; blind, visual impairments)

US Cerebral Palsy Athletic Association
See listing under "General"

US Deaf Bowling Federation
c/o Connie Marchione
8071 Cherrystone Ave
Panorama City, CA 91402
(818) 785-1478 (TTY)
1,2,3 (14 and older; deaf, hearing impairments)

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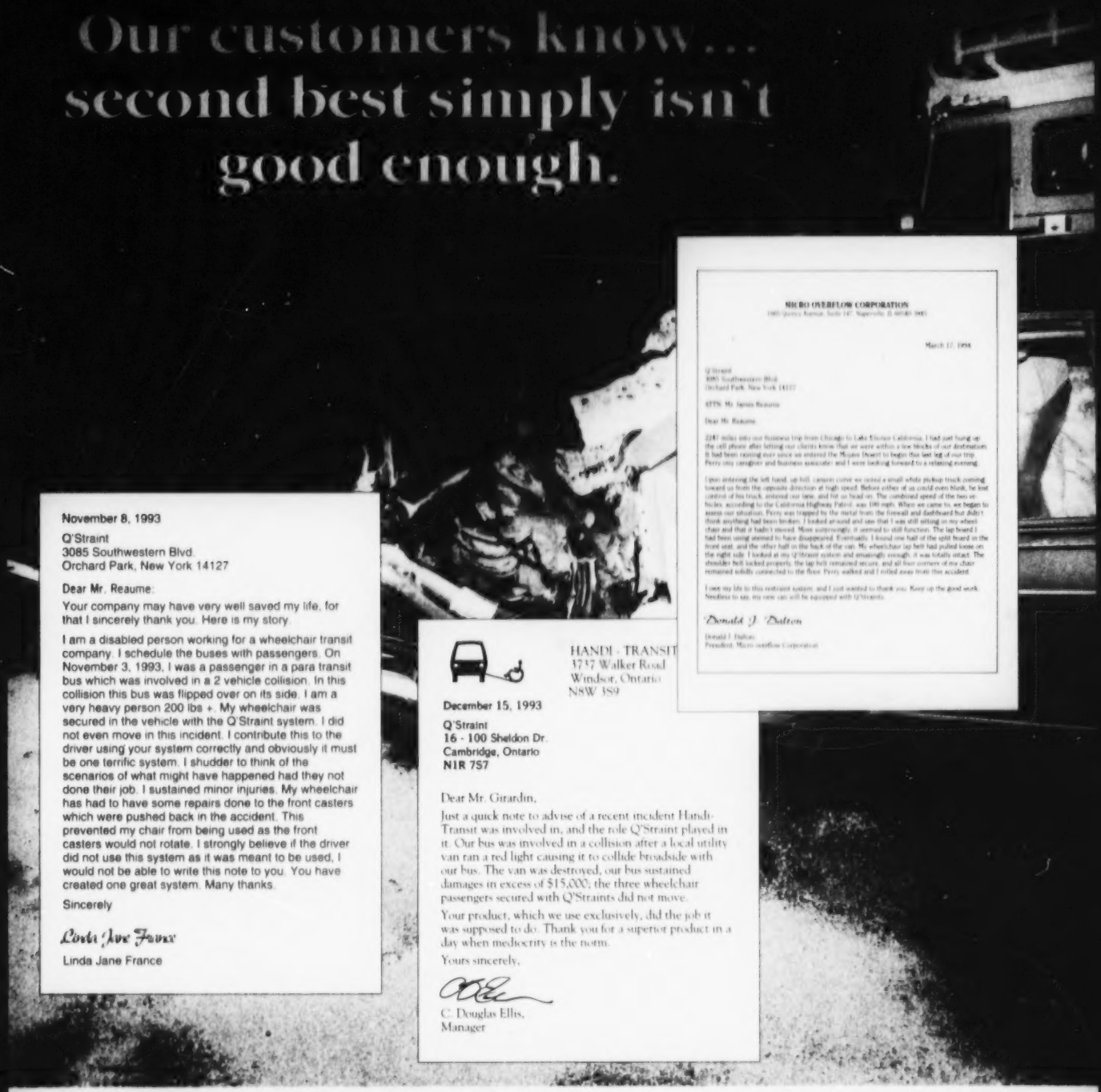
Our customers know... second best simply isn't good enough.



November 8, 1993

Q'Straint
3085 Southwestern Blvd.
Orchard Park, New York 14127

Dear Mr. Reaume:

Your company may have very well saved my life, for that I sincerely thank you. Here is my story.

I am a disabled person working for a wheelchair transit company. I schedule the buses with passengers. On November 3, 1993, I was a passenger in a para transit bus which was involved in a 2 vehicle collision. In this collision this bus was flipped over on its side. I am a very heavy person 200 lbs +. My wheelchair was secured in the vehicle with the Q'Straint system. I did not even move in this incident. I contribute this to the driver using your system correctly and obviously it must be one terrific system. I shudder to think of the scenarios of what might have happened had they not done their job. I sustained minor injuries. My wheelchair has had to have some repairs done to the front casters which were pushed back in the accident. This prevented my chair from being used as the front casters would not rotate. I strongly believe if the driver did not use this system as it was meant to be used, I would not be able to write this note to you. You have created one great system. Many thanks.

Sincerely

Linda Jane France

MICRO OVERFLOW CORPORATION

March 17, 1994

Q'Straint
3085 Southwestern Blvd.
Orchard Park, New York 14127

ATTN: Mr. James Reaume

Dear Mr. Reaume:

2247 miles into our business trip from Chicago to Lake Elsinore California, I had just hung up the cell phone after letting our clients know that we were within a few blocks of our destination. It had been raining ever since we entered the Mojave Desert to begin this last leg of our trip. Perry my caregiver and business associate and I were looking forward to a relaxing evening.

Upon entering the left hand, up hill, canyon curve we noted a small white pickup truck coming toward us from the opposite direction at high speed. Before either of us could even blink, he lost control of his truck, entered our lane, and hit us head on. The combined speed of the two vehicles, according to the California Highway Patrol, was 100 mph. When we came to, we began to assess our situation. Perry was trapped by the metal from the firewall and dashboard but didn't think anything had been broken. I looked around and saw that I was still sitting in my wheelchair and that it hadn't moved. More astonishingly, it seemed to still function. The lap board I had been using seemed to have disappeared. Eventually, I found one half of the split board in the front seat, and the other half in the back of the van. My wheelchair lap belt had pulled loose on the right side. I looked at my Q'Straint system and amazingly enough, it was totally intact. The shoulder belt locked properly, the lap belt remained secure, and all four corners of my chair remained solidly connected to the floor. Perry walked and I rolled away from this accident.

I owe my life to this restraint system, and I just wanted to thank you. Keep up the good work. Needless to say, my new van will be equipped with Q'Straints.

Donald J. Dalton

Donald J. Dalton
President, Micro overflow Corporation

HANDI - TRANSIT
3737 Walker Road
Windsor, Ontario
N8W 3S9

December 15, 1993

Q'Straint
16 - 100 Sheldon Dr.
Cambridge, Ontario
N1R 7S7

Dear Mr. Girardin,

Just a quick note to advise of a recent incident Handi-Transit was involved in, and the role Q'Straint played in it. Our bus was involved in a collision after a local utility van ran a red light causing it to collide broadside with our bus. The van was destroyed, our bus sustained damages in excess of $15,000; the three wheelchair passengers secured with Q'Straints did not move.

Your product, which we use exclusively, did the job it was supposed to do. Thank you for a superior product in a day when mediocrity is the norm.

Yours sincerely,

C. Douglas Ellis,
Manager

Q'STRAINT

For People Who Care™

WHEELCHAIR AND OCCUPANT RESTRAINT SYSTEM

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Circle #251

Q'Straint (USA)
3085 Southwestern Blvd.
Orchard Park, New York 14127
Phone: 716-675-2222
Fax: 716-675-2270

Q'Straint (Canada)
16 - 100 Sheldon Dr.
Cambridge, Ontario N1R 7S7
Phone: 519-622-0000
Fax: 519-622-0021

Circle #91

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406 N. Washington Ave.
Scranton, PA 18503
or call 1-800-747-4988

ACCREDITED CAMP
ACA
American Camping Association

Circle #48

RECREATION

Photo courtesy Canadian Recreational Canoeing Association, Hyde Park, Ontario.

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Cycling

USABA Sports Director for Tandem Cycling
c/o Bill Young
2878 Copley Ave
San Diego, CA 92116
(619) 281-1621
1,2,4,5 (blind)

US Cerebral Palsy Athletic Association
See listing under "General"

US Deaf Cycling Association
c/o Bobby Skedsmo
2625 Copa Del Oro Dr
Union City, CA 94587-3175
(510) 471-9011 (TTY/fax)
1 (unaided bilateral hearing loss of 55 dB or greater)

Fishing

See Also: *"Outdoor Recreation/Wilderness Exploration"*

Fishing Has No Boundaries
PO Box 175
Hayward, WI 54843
(800) 243-3462
(715) 634-3185
(715) 634-1305 (fax)
1,4,5

Photo courtesy Fishing Has No Bounderies, Hayward, WI.

Canoeing

American Canoe Association, Inc.
Disabled Paddlers Committee
7432 Alban Station Blvd, B-226
Springfield, VA 22150
(703) 451-0141
(703) 451-2245 (fax)
ACA Direct@aol.com
1,2,3,4

Canadian Recreational Canoeing Association
1029 Hyde Park Rd, Ste 5
Hyde Park, ON CAN N0M 1Z0
(519) 473-2109
(519) 473-6560 (fax)
3,4,5,6

Cross Country

US Cerebral Palsy Athletic Association
See listing under "General"

Gardening

American Horticultural Therapy Association
362A Christopher Ave
Gaithersburg, MD 20879
(301) 948-3010
(301) 869-2397 (fax)
75352.122@compuserve.com
4

Key to Services

1. ORGANIZES NATIONAL COMPETITIONS
2. ORGANIZES LOCAL COMPETITIONS
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4. PROVIDES INFORMATION (I.E., VIDEOS, PUBLICATIONS)
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6. OFFERS EQUIPMENT USE FOR A FEE
7. PROVIDES FINANCIAL AID

continued on page 80

535

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Designed for OUTDOOR Therapy and fun!

Rock N' Roll takes great pride in providing a device that brings joy to others. Rock N' Roll will customize a cycle for the needs of each individual, such as those with:

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Cerebral Palsy
Partial Paralysis
Amputations
Orthopedic Handicaps
Visual Impairment/Blindness
Muscular Dystrophy

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- ***Communication Aids***
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For more information write or call:
Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle #77

RECREATION

Photo courtesy United Cerebral Palsy Athletic Associatin, Dallas, TX.

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GOAL BALL

USABA Sports Director for Goal Ball
c/o Stephen Kearney, Director of Athletics
Oklahoma School for the Blind
3300 Gibson St
Muskogee, OK 74403
(918) 682-6641 (days)
(918) 683-0338 (evenings)
(918) 682-1651 (fax)
oksb@gteens.com
1,2,3,4,5,6,7 (8–45 years; visual impairments)

HORSEBACK RIDING

North American Riding for the Handicapped Association
c/o Bill Scebbi
PO Box 33150
Denver, CO 80233
(800) 369-7433
(303) 452-1212
1,2,3,4

ICE HOCKEY

American Hearing Impaired Hockey Association
c/o Irv Tiahynbik
1143 W Lake St
Chicago, IL 60607
(312) 226-5880
(312) 829-2098 (fax)
1,3,7 (10–20 years; unaided bilateral hearing loss of 55 dB or greater)

OUTDOOR RECREATION/WILDERNESS EXPLORATION

Breckenridge Outdoor Education Center
PO Box 697
Breckenridge, CO 80424
(303) 453-6422
(303) 453-4676 (fax)
2,3,4,7

Cooperative Wilderness Handicapped Outdoor Group
Box 8118, Pond Student Union
Idaho State University
Pocatello, ID 83209
(208) 236-3912
(208) 236-4600 (fax)
3,4,5,6,7

Courage Center
3915 Golden Valley Rd
Golden Valley, MN 55422
(612) 520-0520
(612) 520-0577 (fax)
2,4,5 (physical disabilities)

Photo courtesy Breckenridge Outdoor Education Center, Brekenridge, CO.

Environmental Traveling Companions
Fort Mason Center
Landmark Bldg C
San Francisco, CA 94123
(415) 474-7662
(415) 474-3919 (fax)
3,4,7 (10 and older)

continued on page 82

Photo courtesy Breckenridge Outdoor Education Center, Brekenridge, CO.

537

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Beverly Hills, CA 90210

CA & NY Residents add 8.25% sales tax.

Circle # 184

938

RECREATION

Photo courtesy *Sports 'N Spokes*/Paralyzed Veterans of America, Phoenix, AZ.

KEY TO SERVICES

1. ORGANIZES NATIONAL COMPETITIONS
2. ORGANIZES LOCAL COMPETITIONS
3. TRAINS LEADERS, SUCH AS COACHES AND PARENTS
4. PROVIDES INFORMATION (I.E., VIDEOS, PUBLICATIONS)
5. OFFERS FREE LOANER EQUIPMENT TO PARTICIPATE IN PROGRAM (I.E., RACING WHEELCHAIRS)
6. OFFERS EQUIPMENT USE FOR A FEE
7. PROVIDES FINANCIAL AID

continued from 80

National Park Service
Office on Accessibility
800 N Capitol NW, Ste 580
Washington, DC 20002
(202) 343-3674
(202) 343-4230 (fax)
Provides accessibility information for national parks

Paraplegics on Independent Nature Trips
c/o Carol Barrett
4144 N Central Expwy
Dallas, TX 75204
(214) 827-7404
(214) 414-3772 (fax)
1,2,4,5 (physical disabilities)

Wilderness Inquiry
1313 Fifth St SE, Box 84
Minneapolis, MN 55414
(800) 728-0719
(612) 379-3858
(612) 379-5972 (fax)
4,5,7

PERFORMING ARTS

Association for Theatre and Disability
c/o Access Theatre
527 Garden St
Santa Barbara, CA 93101
(805) 564-2063
(805) 564-2424 (TTY)
(805) 564-0051 (fax)
Rippyrod@aol.com
Maintains national talent bank of artists with disabilities, organizes national conference on accessible theater every August

continued on page 84

Photo courtesy The Cooperative Wilderness Handicapped Outdoor Group, Pocatello, ID.

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Mobility
Videos

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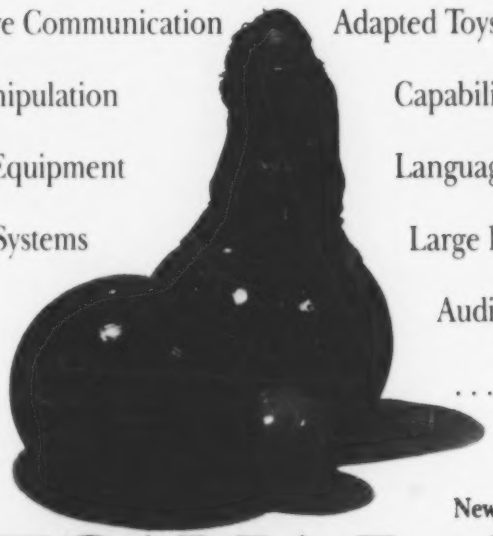

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Circle #63

539

PRODUCT NEWS

Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily litt and store the buggies in a car trunk. Great for indoor or outdoor use.

Full Range of Accessories

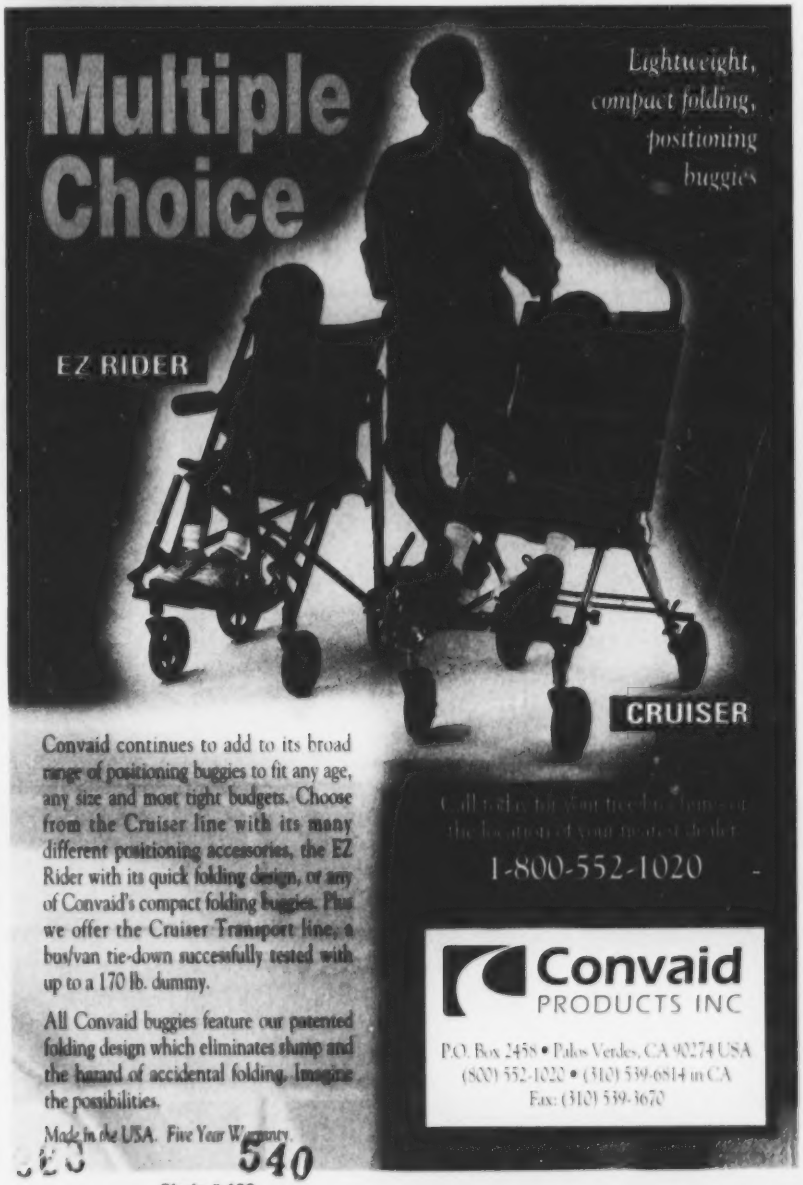
A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.

New Bus/Van Tie-Down Models

Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.

Good Looks, and Custom Comfort Make Kids Smile

Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability.


Multiple Choice
Lightweight, compact folding, positioning buggies
EZ RIDER
CRUISER
Convaid continues to add to its broad range of positioning buggies to fit any age, any size and most tight budgets. Choose from the Cruiser line with its many different positioning accessories, the EZ Rider with its quick folding design, or any of Convaid's compact folding buggies. Plus we offer the Cruiser Transport line, a bus/van tie-down successfully tested with up to a 170 lb. dummy.
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Circle #123

RECREATION

continued from 82

POWERLIFTING

US Cerebral Palsy Athletic Association
See listing under "General"

QUAD RUGBY

Wheelchair Sports, USA
See listing under "General"

RACQUETBALL

National Wheelchair Racquetball Association
c/o Geno Bonetti
Director of Spinal Cord Programs
Healthsouth Rehabilitation Hospital of Pittsburgh
2380 McGinely Rd
Monroeville, PA 15146
(412) 856-2468
(412) 856-2437 (fax)
1,2,3,4,5 (wheelchair users)

SAILING

Access to Sailing
c/o Duncan Milne
19744 Beach Blvd, Ste 340
Huntington Beach, CA 92648
(714) 722-5371
2,3,4,5 (6 and older)

National Ocean Access Project
PO Box 10246
Rockville, MD 20849
(301) 217-9842, ext 6
1,2,3,4,5,6

Ontario Sailing Association
Committee for Sailing for Disabled Persons
1185 Eglington Ave E
North York, ON CAN M3C 3C6
(416) 426-7271
(416) 426-7344 (fax)
1,2,3,4,5,6

Photo courtesy The Cooperative Wilderness Handicapped Outdoor Group, Pocatello, ID.

US Sailing Association
Committee on Sailors with Special Needs
PO Box 209
Newport, RI 02840
(401) 849-5200
(401) 849-5208 (fax)
US Sailing@compuserv.com
1,3,4,6

SCUBA

Moray Wheels: Adaptive Scuba Association
PO Box 1660 General Mail Facility
Boston, MA 02205
(603) 598-4292
3,4,5 (14 and older; physical disabilities)

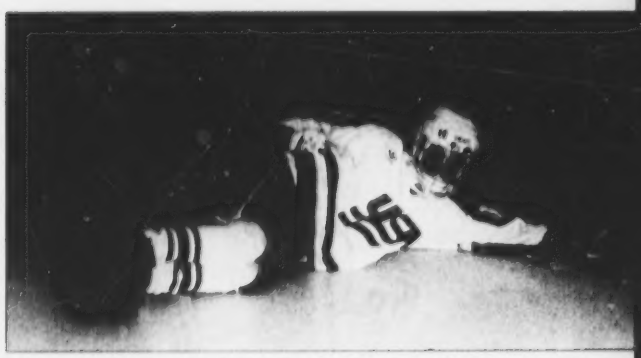


Photo courtesy American Sledge Hockey Association, Bloomington, MN.

541

National Instructors Association for Divers with Disabilities
PO Box 112223
Campbell, CA 95011
(408) 379-6536
✉ dshrout@aol.com
3,5,6

Skiing

Canadian Association for Disabled Skiing
Box 307,
Kimberley, BC CAN V1A 2Y9
(604) 427-7712
(604) 427-7715 (fax)
1,4,5,6

US Deaf Skiers Association
c/o W. Edward Ingham
0400 Palatine Hill Rd
Portland, OR 97219
(503) 245-2192 (TTY)
(503) 246-3757 (fax)
✉ Edlngham@aol.com
1,2,3,4,7

Slalom (for wheelchairs)

US Cerebral Palsy Athletic Association
See listing under "General"

Sledge Hockey

American Sledge Hockey Association (ASHA)
c/o John Schatzlein
10933 Johnson Ave S
Bloomington, MN 55437
(612) 750-3973
(612) 888-5331 (fax)
1,3,4,5 (11–21 years; mobility impairments)

Soccer

US Cerebral Palsy Athletic Association
See listing under "General"

Softball

National Softball Association of the Deaf
c/o Vance Rewolinski
6605 Krolton Dr.
Austin TX 78745
1,2

National Wheelchair Softball Association
c/o Jon Speake
1616 Todd Ct
Hastings, MN 55033
(612) 437-1792
1,5

Table Tennis

American Wheelchair Table Tennis Association
c/o Jennifer Johnson
23 Parker St
Port Chester, NY 10573
(914) 937-3932
(914) 937-3932 (press *51 for fax)
1,2,4 (4 and older)

Team Handball

UCPAA Team Handball Technical Officer
c/o Bill Wilkie
UCPA of Greater Hartford
80 Whitney St
Hartford, CT 06105
(203) 236-6201
(203) 236-6205 (fax)
1,2,3,4 (12 and older; physical disabilities)

Photo courtesy *Sports 'N Spokes*/Paralyzed Veterans of America, Phoenix, AZ.

Tennis

International Foundation of Wheelchair Tennis
Peter Burwash International
Attn: Director-Special Programs
2203 Timberloch Pl, Ste 126
The Woodlands, TX 77380
(713) 363-4707
(713) 292-7783 (fax)
✉ PBI@infohwy.com
1,2,3,4,5

National Foundation of Wheelchair Tennis
Brad Parks, Executive Director
940 Calle Amanecer, Ste B
San Clemente, CA 92672
(714) 361-3663
(714) 361-6603 (fax)
1,2,4 (7 and older; physical disabilities)

Track and Field

US Cerebral Palsy Athletic Association
See listing under "General"

Wheelchair Sports, USA
See listing under "General"

Water Skiing

American Water Ski Association
Committee on Water Skiing for the Disabled
799 Overlook Dr
Winter Haven, FL 33884-0799
(800) 533-2972
(813) 324-4341
(813) 325-8259 (fax)
✉ 73024.3504@compuserve.com
1,3,4

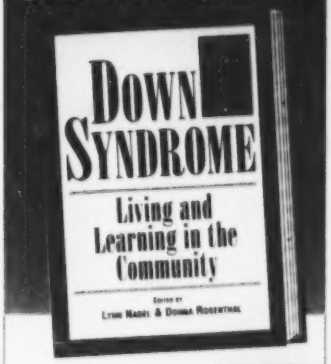
Weightlifting

US Wheelchair Weightlifting Federation
c/o Bill Hens
39 Michael Pl
Levittown, PA 19057
(215) 945-1964
organizes international team for competition (16 and older; physical disabilities)

Wrestling

US Deaf Wrestling Association
c/o James Schartner
4835 Mt Zion Rd
Frederick, MD 21702
(301) 473-5255
1,2,3 (18-34; deaf)

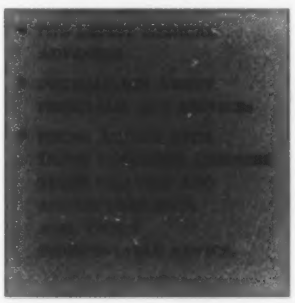
An invaluable guide for parents and healthcare providers alike —



With a Foreword by Chris Burke

Down Syndrome: Living and Learning in the Community, written under the auspices of the National Down Syndrome Society, provides state-of-the-art information and advice.

This book will prove an invaluable tool for parents and health care professionals, enabling people with Down syndrome to cope with the problems they face and participate to the fullest in community life.



Lynn Nadel is a Professor of Psychology at the University of Arizona.

Donna Rosenthal is a past Executive Director of the National Down Syndrome Society.

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Circle #241

Using Ordinary Toys for Kids With Special Needs:

Outdoor Fun

by Joanne and Stephanie Oppenheim

For more than 100 suggestions on how to easily adapt ordinary toys for kids with special needs, look at the 1995 edition of **The Best Toys, Books & Videos for Kids** ***(HarperCollins, $12)*** by Joanne and Stephanie Oppenheim. The book is a comprehensive guide to more than 1,000 classic and new products for children from infants to preteens. Available through Exceptional Parent Library, (800) 535-1910.

Getting into the big outdoors is one of the delights of summer. Outdoor play is a time to let loose, to shout and laugh out loud without worrying about making too much noise or bothering neighbors. It's a time for flexing, stretching, using muscles and getting a sense of one's physical self. It's often a social time when kids learn the give-and-take of playing with others. Well-chosen toys can build children's confidence about themselves as "doers." Here are some ordinary toys for outdoor fun that may require little or no adaptations for children with disabilities.

Following each toy's name in parentheses is the name of its manufacturer, the recommended retail price and a customer service number that may be used for ordering or for more information.

Musical Bubble Tunes

(CAP, $9.99; 216/292-6363)

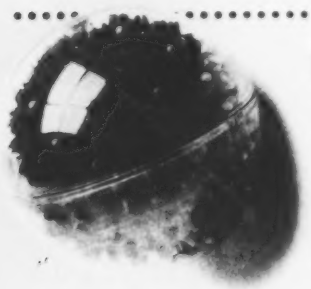
Kids who may not be able to blow bubbles can still have the thrill of creating a rush of bubbles with a push of a button. This bubble toy plays music when another button is pushed. It plays "Happy Birthday" and seven other tunes. Requires two AA batteries.

Airplane Swing

(Little Tikes, $25-$28; 800/321-0183)

A parent told us how useful this airplane swing with its high back has been for her three-year-old who needs extra support for sitting. Tots practically wear this jolly airplane that holds them all around with leg holes and no place to slip through. Has an adjustable seat belt. Can accommodate children up to 50 pounds.

Activity tip: *Use words like "faster" and "slower," "higher" and "lower," "stop" and "go" to reinforce these concepts in active, meaningful ways. Play pretend games in which your tot is flying to a faraway place; talk about what the child can "see" as he or she flies.*



Roll 'n Rattle Ball

(Playskool, $9.99; 800/752-9755)

It takes very little to activate this wonderful rolling toy, but children get visual as well as sound feedback from the multi-colored, tiny beads that swirl and swish in this see-through sphere with a bright yellow and blue ball inside. The toy is not for throwing, but it's ideal for stimulating children to crawl after and swat at with whole-hand movement; use also for roll-back-and-forth social games. Needs no adaptation.

Activity tip: *To motivate and involve an older child, use the ball for a guessing game. Will the ball stop yellow side up or blue? Let the child guess. Then take turns spinning the ball and chant "Round and round she goes. Yellow or blue; which one mostly shows?" Of course, both colors will show, but*

543

Double Fun Wagon

(Today's Kids, $33-$45; 800/258-8697)

This innovative wagon is designed to double as a hauling or ride-in vehicle. The floor of the wagon can be closed or opened halfway to the ground so kids with disabilities can sit in it as passengers or use their legs to help it move. The handle works at child-height or telescopes for an adult to pull.

Adaptation idea: *For a child who needs extra support, a seat belt with Velcro closings can be added to the high back of the wagon.*

Crayola Magic Sunlight Prints

(Crayola, $14.99; 800/272-9652)

Printing images with the sun on light-sensitive paper is like magic! This kit comes with clear directions, markers, a glitter-glue pen, acetate images, frames, stencils and 15 pieces of special print paper. Gives pleasing results for kids who may not be able to draw with conventional art tools. A little art, a little science, a lot of fun!

Drive-In Playhouse

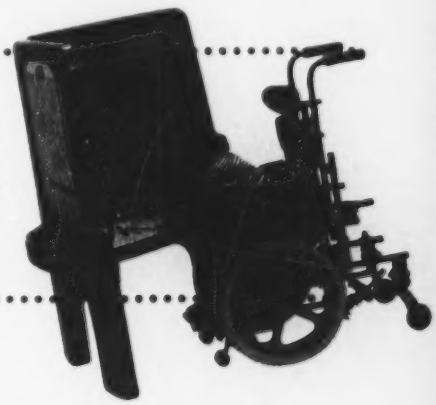
(Step Two, $155; 800/347-8372)

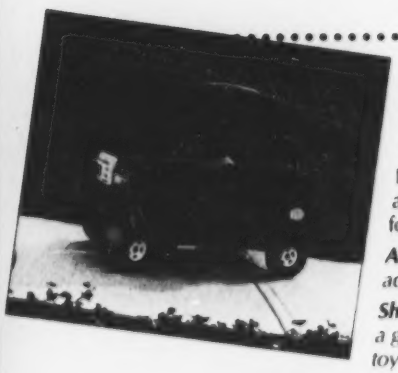
A playhouse that meets today's building codes. With its double door opening (22.25 inches wide), a small wheelchair can roll right into this playhouse that has big windows, a built-in table and a cordless phone.

Creative Art Center

(Step 2, $45-$50; 800/347-8327)

A young artist in a wheelchair can sit at the work table and paint or color. Can be used indoors or outdoors by one or several children at a time. There's room at the table for painting, chalk or crayon drawing and desktop publishing.





Pickup Truck

(Little Tikes, $75-$80; 800/321-0183)

Newest in the fleet of sturdy ride-in vehicles, this foot-to-floor (no pedals) truck can build upper- and lower-body coordination and imagination. Doors open for easy in and out and there's room for cargo. Includes a working tailgate.

Adaptation idea: *For a child who needs extra support, a seat belt with Velcro closings can be added to the high-backed seat.*

Shopping tip: *Battery-operated ride-in cars that can be activated with the touch of a button may be a good choice for kids who are unable to pedal or propel a foot-to-floor vehicle. However, such toys are expensive, and require constant supervision and regular battery recharges.*

"These products were reviewed by the Oppenheim Toy Portfolio, an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS; it also publishes a quarterly newsletter. Both publications include learning activity ideas and ways to adapt ordinary products for kids with special needs. To subscribe to the newsletter send $12 to The Oppenheim Toy Portfolio, 40 East 9th, Suite 14m, New York, NY 10003."

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- Feeding Disorders
- Behavior Problems
- Down Syndrome
- Other Special Needs

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Circle #70

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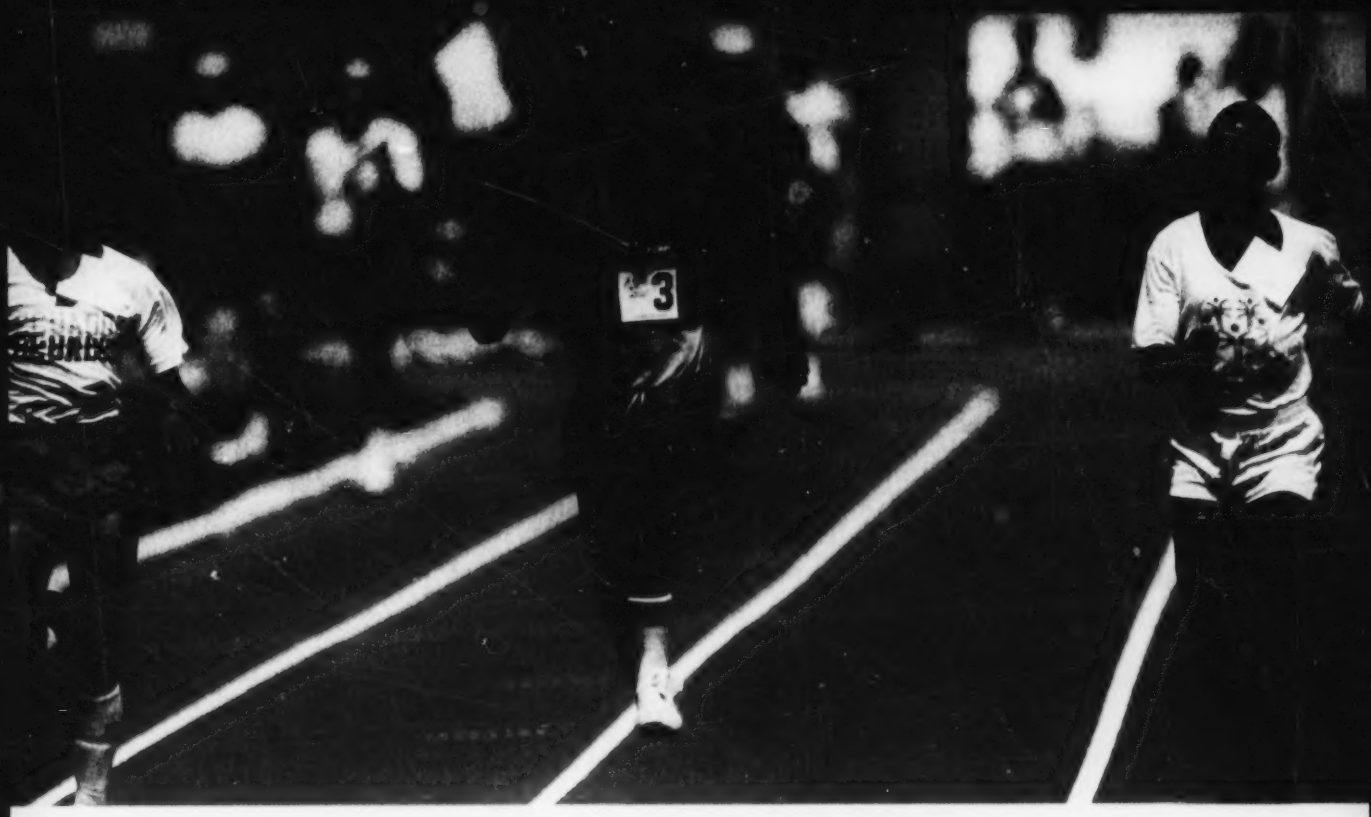
Circle #40

545



You've seen the gifts of our athletes.

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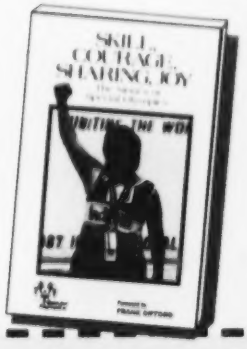

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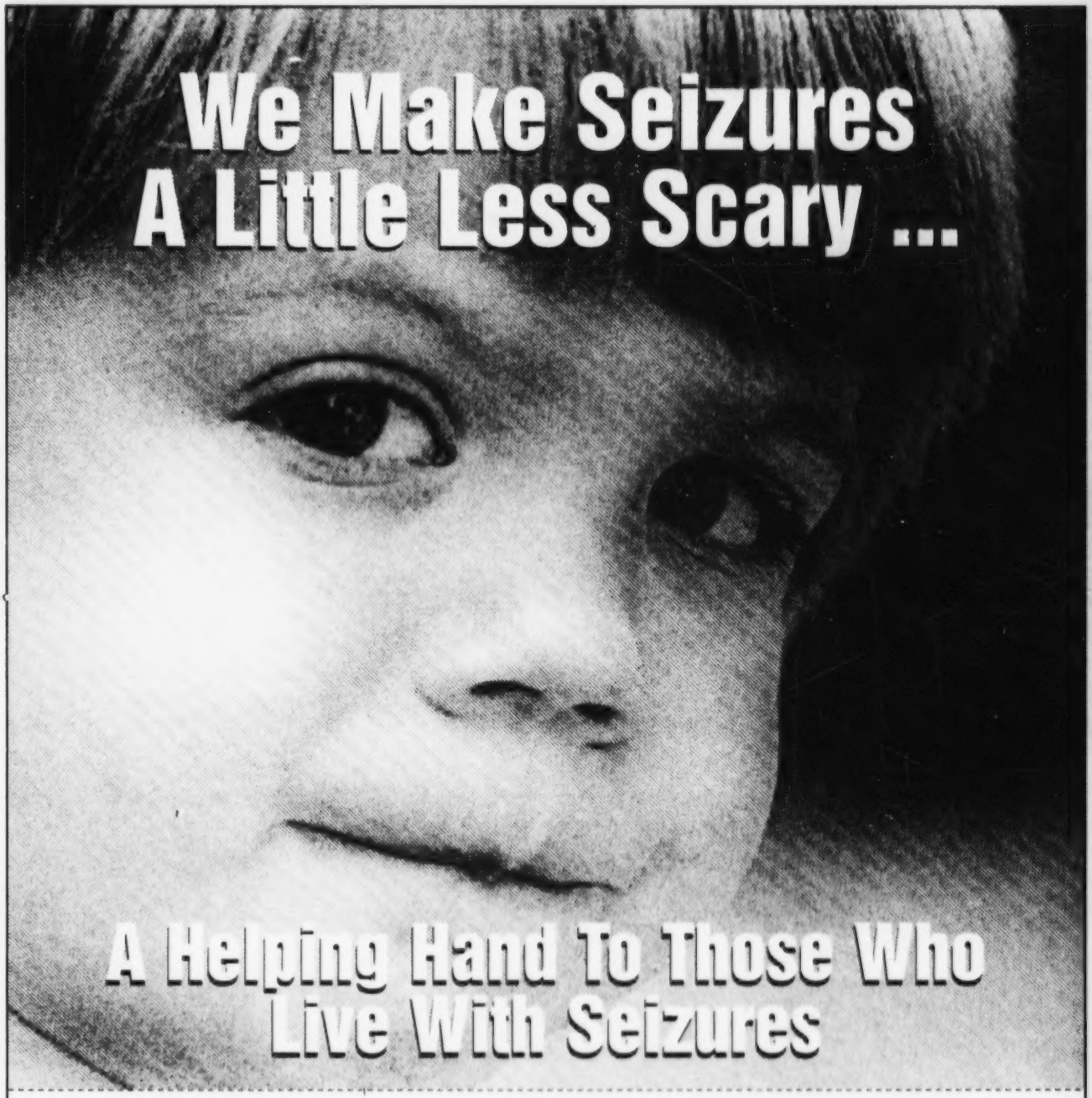

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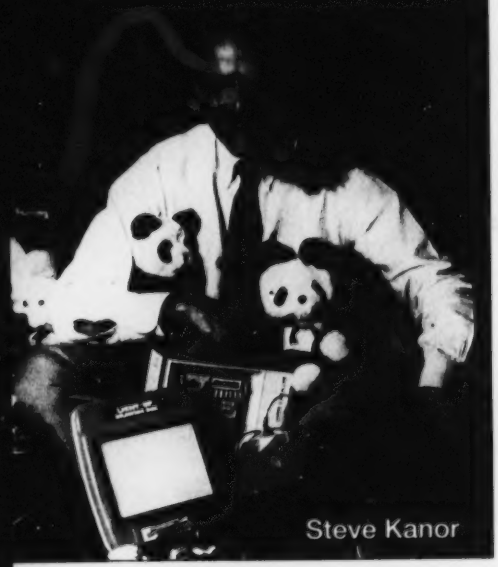
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Circle # 160

Talking With Your Child About Disabilities

by Chad Pierro

I remember my first day of kindergarten because of the isolation I felt. I was used to getting occasional glances on the street, in the local shopping mall, or at the grocery store, but never had I experienced the intensity of the stares I got from my new classmates. Before this, it had been obvious to me that I was different, but this difference was magnified when I walked through the classroom door.

Having cerebral palsy has been a part of my life since I was born, but as a young child, my disability was never really discussed. Maybe it was because I had no questions and just accepted things as they were, maybe because my parents didn't want to flood my mind with my physical condition—for whatever reason, we just didn't talk about it.

But when I came home from school that day, the questions came in a flurry—"Why was everyone looking at me? Why am I different from everyone else? Am I going to have any friends?"

I remember being comforted by my mother and father, but more than that, I remember getting answers to each question I asked. My parents laid things out for me in a clear manner that I understood; I was given practical ideas to deal with my feelings, and I was made to feel okay with the person I was. Once I rose above my insecurity, I was able to take control of the situations I later encountered.

It can be difficult to talk openly with your child about his or her disability or chronic illness. You don't want to make it the center of attention, yet you do want your child to understand his or her condition, as well as the different feelings and limitations that go along with it.

Few parents want their kids defined purely by a diagnosis. It is essential for children and teenagers with disabilities to be aware of specific issues that may affect their everyday lives so they are able to emphasize their personalities, not their disabilities.

You would be hard-pressed to find a child or teenager who enjoys sitting through a lecture given by a parent. Usually, lectures are seen as condescending sermons, not offerings of information. What works better is answering questions when they are asked, and suggesting ideas when appropriate. What is "appropriate" depends largely on your relationship with your child, but it is safe to say that occasional advice is more welcome than constant preaching.

Honesty is crucial in all parent-child relationships, and it is no less important when discussing disabilities with your child or teenager. So, when questions are asked—"What's wrong with my legs" or "Why can't I keep up in school?"—give answers that are understandable and truthful. Try to give complete answers because children can often sense when you are keeping things from them.

Some parents have the tendency to hold back information, wanting to spare their son's or daughter's feelings. What they fail to realize is that, in the long term, being given correct information at an early age is very good for healthy development. And, if kids are informed, they can answer questions themselves, rather than depending on Mom or Dad to speak up for them.

Learning about a disability or a chronic illness does not happen in a single session; rather, it is a process that continues over time. For this reason, it is often a good idea to encourage your children to participate in different activities they may enjoy. Children can be involved in summer camps, sports teams or school-related functions. A variety of experiences gives children and teenagers an idea of what they are able to do, as well as things they can do less easily.

Remember that, in many ways, children with disabilities develop similarly to children without disabilities. It makes sense then, to give kids information that helps them understand not only their differences, but also what they have in common with other children. With this knowledge, children with disabilities will be able to become comfortable with who they are, and who they can be. **EP**

Chad Pierro grew up in the Twin Cities area of Minnesota. He is a graduate of Minnetonka High School and Augsburg College, with degrees in English (B.A.) and Psychology (B.S.). Chad works as a transition specialist for Project Youth, a program of the PACER Center, a Minneapolis-based family advocacy agency. In his work, Chad works with teenagers who have disabilities of all types and helps them work through the issues and difficulties they may be facing in their transition to adult life.

This article was adapted with permission from the PACESETTER, June 1994. The PACESETTER is a free newsletter published three times a year by the PACER Center. For a sample copy, send a 9 x 12 envelope with $1.00 postage to the PACER Center, 4826 Chicago Ave. S., Minneapolis, MN 55417.

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READERS TALK ABOUT:
Helping a Child Learn About His or Her Disability

A few months ago, we asked readers to share their experiences of talking with children about their disabilities. But as the mail started to arrive at our editorial offices, we realized the question we'd asked may have been too limiting. Most of the stories we read involved more than "talking"—indeed, in some cases, what parents did not say turned out to be more important than what they did say.

The parents who share their stories with us this month realize that learning about a disability or chronic illness involves more than a few conversations. Indeed, it will be a lifelong journey for both parent and child. For children, the process will certainly involve talking with parents, but it will also include discussions with peers, meeting adults with disabilities and having opportunities to take on new challenges in order to learn what they can do.

❑❑❑❑❑

Following My Heart

My children, Heather and Logan, were born with Miller syndrome, an extremely rare genetic condition which causes multiple physical anomalies including facial differences, shortened and bowed forearms, missing or webbed fingers and toes, and abnormal growth of the bones in the lower legs. Even after many years of living with children who have physical differences, I am still surprised at the situations that arise to remind me that my parenting experiences are very different from those of others. Just when everything is going smoothly and my life starts to seem quite "normal," I find myself facing a problem I'm not sure how to handle…

Ready to open the gifts: (from left) Logan, 14, Debbie and Heather, 17, on Christmas morning 1994.

Playing basketball

When Logan was eight years old, he decided he wanted to play basketball. I didn't know how to react. His hands were so small and his fingers didn't straighten. How could he play basketball?

I have always encouraged both of my children to do all the things they wanted to do. I've tried not to discourage them because I don't always know what is possible. But if I encouraged Logan's basketball ambitions, he might get too-high expectations, making the realities of his limitations more disappointing. On the other hand, if I discouraged him, he might not try to achieve his goals in the future. I would never want him to give up without trying.

I called the coach and told him about Logan. He recommended that Logan come to the practice at which teams would be chosen. If Logan decided he wanted to play, the coach would work with him. If he decided not to play, at least he would have tried.

When the big night came, Logan lined up with the other boys who were dribbling the ball up and down the floor. I could see it was difficult for him to control the ball, but he hung in there and completed the exercise. The teams were assigned and Logan ended up on a team with a couple of his friends.

Each week, Logan looked forward to the games. He always played in spite of his difficulties. But as the weeks went by, I could see he was becoming discouraged. He realized the other boys weren't passing the ball to him, and he knew it was because they were afraid he couldn't catch it. His teammates were very nice to him and very supportive, but they wanted to win games.

Finally, it was the last game, the last quarter, the last minute of play. The ball ended up in Logan's hands. He jumped and shot. The ball went in. The crowd roared. Logan beamed. I felt so much happiness to see my son succeed.

The next year, Logan chose not to join the basketball team. I think he could sense the competitiveness of the boys his age. I didn't detect any regrets on his part, just calm acceptance of the way things were. I believe peace comes from acceptance, especially after you've given the situation everything you've got to give.

The pageant

As girls reach junior high, they start receiving mail that would interest teenage girls. One day, Heather was excited to receive such a letter addressed to her. She opened it to find information about an upcoming Miss Teenage America Pageant. She read the letter and approached me with a beaming smile.

continued on page 94

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT. In upcoming months, readers will be talking about:

- education options—special schools or inclusion? (September; deadline July 1, 1995)
- children's favorite toys and playtime activities (October; deadline Aug. 1, 1995)
- technology—how has it made a difference for your child? (November; deadline Sept. 1, 1995)
- grandparents/extended family (December; deadline Oct.1,1995)

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

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continued from page 93

She proudly told me she would like to enter the contest.

I felt an incredible pain in my heart. I didn't know if I should encourage Heather to enter a "beauty contest." On the other hand, I didn't want to tell her she couldn't try.

I asked Heather if she had read the qualifications for pageant participants. I pointed out the third rule which stated that participants must be in good health.

Heather said she had read all the rules and felt she met that requirement because doctors always say she is healthy.

"Yes," I agreed, "you are healthy for someone with Miller syndrome. But are you healthy in comparison to people who do not have Miller syndrome?"

"Oh," she said, "when you put it that way, maybe not."

I suggested that Heather call the pageant director and tell that person about herself. She immediately went to the phone. I told her to wait a minute because it was a long distance call and she needed to think about what she was going to say. I suggested she write out the questions she would ask and a description of herself.

A few minutes later, Heather returned. "This isn't going to work," she told me, "If I describe myself over the phone, the person will think I look like a freak!"

Again, my heart ached. I suggested she write a letter describing herself and send a picture. That way the person could see her too. She agreed this was a good idea.

A few days later, Heather came to me again. She told me she had been doing some more thinking and had decided against entering the contest. I asked her why. She replied that if she were watching a pageant like this one on television and saw someone who looked like her, she would think it was weird. After realizing that, she told me, she had decided not to enter.

I felt both relief and sadness. I was relieved that I didn't make the decision for Heather by discouraging her when she first approached me. But I was sad to think that because Heather looks different, she will not be able to do some of the things other teenage girls can do.

At the same time, I had to admire Heather for her courage and self-confidence. When I was her age, there would have been no physical reason to prevent me from entering a pageant. However, I never had the courage or self-confidence to even consider it.

Proud of me, too

I am very proud of both of my children. And sometimes, I have to feel a bit proud of myself, too. I am glad I was able to follow the direction my heart took me when these situations came up in the first place.

—Debbie Madsen
Salt Lake City, Utah

Debbie Madsen is a frequent contributor to ALL ABOUT ME, the newsletter of the Foundation for Nager and Miller Syndromes (FNMS, 333 Country Ln., Glenview, IL 60025; 800/507-3667). This article was adapted from two articles originally published in ALL ABOUT ME. For more information about Miller or Nager syndromes, contact FNMS.

MORE READERS TALK on page 96

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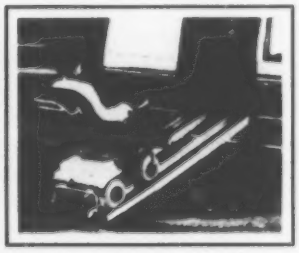

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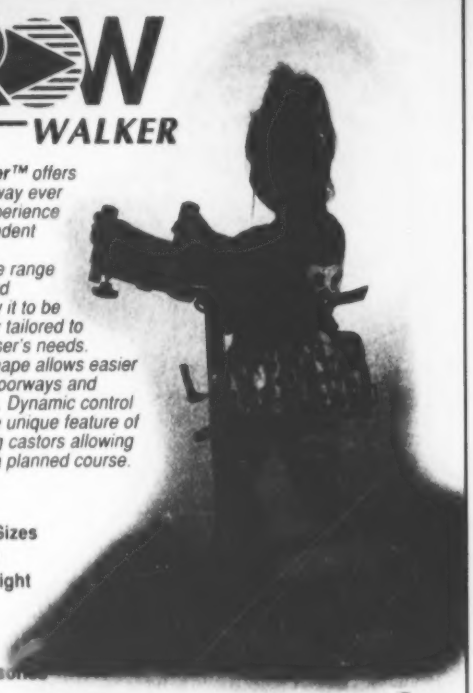

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She Needed to See Winners

My daughter, Danielle, was born with spina bifida. Helping her accept her physical differences started at birth. People often asked, "What's wrong with her?" We always started our answer by rephrasing the question—"Well, what is *different* about Danielle is..."

From the time she was little, we made sure Danielle was exposed to adults and other kids in wheelchairs. I also read her as many stories about wheelchair users as I could find.

By the age of three, she knew she was different, but that difference didn't have a good or bad connotation. However, in kindergarten, Danielle started to think it was a bad thing to have spina bifida. Her classmates told her she would never get married and couldn't dance. She would come home from school sad and angry. I knew no words from me could change her negative feelings. She needed to see winners.

We started going to wheelchair basketball games. Danielle became involved in wheelchair tennis where she met lots of kids like herself. She also met married and working adults in wheelchairs.

Danielle is now nine years old. She continues to ask questions and struggle with her differences; I know this process will be a lifetime journey. I feel strongly that being with others like herself—both children and adults—is the best way for her to learn. As she has told me many times, "You really don't know what it's like, Mom."

—Diane Mitchell
Salem, Oregon

❑❑❑❑❑

Learning the "Ability Words"

Talking to Jason about his disabilities came out of other people talking *about* Jason. Like in the grocery store, after Jason made a particularly loud remark about whether or not fish pass gas, a woman came up to me and said, "I know just what you're going through. We had one like him in our family too."

Later, Jason asked me, "Does that woman have a little boy like me? What does she mean? Like me, how?"

These situations were only compounded by educational and medical situations in which Jason was referred to as moderately retarded, visually-impaired, hyperactive, dysmorphic, seizure-disordered, multi-handicapped, even "syndromy." I had to ask myself, "What's a fella to think about himself while dodging all these 'diagnoses?'"

Jason (right) and older sister Jennifer enjoy themselves at a church party in 1993.

I didn't feel fully prepared to tackle this ever-increasing army of adjectives aimed at Jason. So, over a period of time, I began asking everyone involved with Jason to tell me how they saw him, without naming one thing having to do with his disabilities.

I heard things like, "He's a hoot, a very funny kid; he's so observant—notices the smallest things; his sense of smell is uncanny; he has remarkable recall; he has such curiosity; he makes me laugh." To me, these things were so much more Jason, and so much more important for Jason to learn about himself. My plan was taking shape—I wanted to start talking to Jason about his abilities, not just his diagnoses.

We began in the Wal-Mart parking lot, actually. While walking from the car to the store, Jason began his litany of smells—nose down, sniff, sniff—"I smell diesel, road tar, oil, gas."

I replied, "Yes, you do smell them, Jason. You have a great gift of smell. Did you know that about yourself?"

Time after time, I identified Jason's abilities for him. I explained how these "ability words" were not in his diagnosis, and how the words that labeled him were not adequate to tell *who* he was but just said things *about* him.

The terrible taunts—called "teasing" by the people who do it—have been the hardest thing for me to help Jason deal with. It became my goal to disarm these labels and insults. "Some people only know the diagnosis words," I told Jason, "labels like 'retarded.' They haven't learned the other words that tell about you. You will have to be smarter than they are and learn the ability words."

And so, at a neighborhood Christmas party, as the adults gathered in the kitchen, we heard a child's voice from the den, "What's the matter with you? Are you a retard or something?"

The adults fell silent. Husbands and wives looked at each other, wondering whose child had slung the "R-word" at Jason.

But Jason was equipped to handle the situation. We heard him reply, "'Retard, yes, absolutely. And I smell real good, too."

A roar of laughter arose from the den and spread through the kitchen. I did not attempt an explanation; it wasn't necessary. I thought to myself, "Jason is a hoot, a very funny kid—he makes us laugh."

—Jan Moss
Oklahoma City, Oklahoma

More Readers Talk on page 98

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Circle #11

Practice!

Last Saturday, my husband, Rod, took our four-year-old daughter, Leah, to the grocery store. Leah has cerebral palsy and uses a wheelchair. She's very clever and funny—a real joy to be with.

She was watching a little girl about her age, when she suddenly turned to Rod and said, "Dad, I can't walk!"

It was one of those moments you dread, but Rod was ready. He bent down and kissed her and said, "I know, sweetie, but that's okay. We love you just the way you are."

I'm so proud of him, but not in the least bit surprised. You see, we've *always* talked about Leah's cerebral palsy with her. I can't figure out the parents who don't talk about a child's disability. Do these parents want to turn the disability into a subject that's too difficult or embarrassing to discuss?

I'll never forget my mother's attempt to talk to me about sex when I was 12. She couldn't look me in the eye and the whole ordeal was obviously so painful to her that I ended up in tears, begging her to stop! I don't ever want something as important as Leah's cerebral palsy to take on that "taboo" quality. Leah's disability is part of who she is and we embrace all of her. It's not a secret, or something we're ashamed of, so we talk, talk, talk until we're finally able to do so in a calm and sensible way.

A friend of mine, whose child also has cerebral palsy, can scarcely cough out the letters "C-P" without choking on them. That's not the message she wants her son to pick up on, so she asked me, "How do you do it?"

I said, "Practice!" Tell everyone who crosses your path. Tell your neighbors. Tell your waitress. Tell the cashier at the grocery store. Only if it's a daily occurrence can you learn to talk about it matter-of-factly.

Taking a breather after some serious apple picking are (clockwise from left) Cara and Rod McCulley, Leah, 4, and Jake, 2.

Practice talking about it with your child, especially while they are still young. I'm just as glad Leah won't remember some of my first awkward attempts. I don't recommend going overboard and beating it into the ground, but if the subject comes up—and it will—don't hide from it. Watch your child's reaction; you might be amazed to see relief when you explain why certain things are so difficult for him or her.

We are still learning about the impact Leah's cerebral palsy is going to have on our lives. But you can bet I'm going to include Leah in this process, every step of the way. And when people feel awkward about her disability or don't know what to say, I know that my kid—having talked about it all her life—will have what it takes to set them at ease. It's just a small part of our overall plan to teach Leah total self-awareness and acceptance, genuine self-esteem and the self-confidence to tell you all about it.

—Cara McCulley
Johnson City, New York

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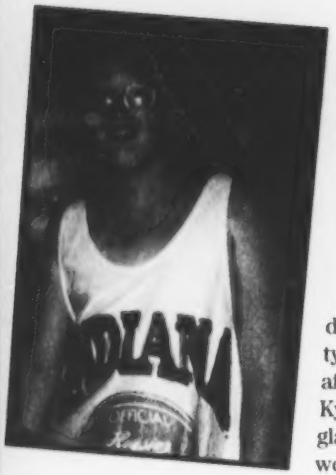

Star of the Team

Ectodermal dysplasia (ED) is a genetic condition involving abnormalities of the ectoderm (skin and its derivatives). There are many types of ED; our son, Kyle, is affected with hypohidrotic ED. Kyle has a total lack of sweat glands, total absence of teeth (he's worn a full set of dentures since age two) and sparse hair follicles (last year, he finally had enough hair to get his first "trim").

Kyle's inability to sweat results in heat intolerance and fevers of unknown origin. Most of these episodes may be avoided by environmental adaptations—staying in air conditioning, finding shade and, when necessary, wetting him down with cool water.

Our family has always had a rule that you must be 10 years old to play football. Last fall, Kyle turned 10 and, you guessed it, he *really* wanted to play. Kyle already plays baseball and basketball in organized youth sports programs. I told him he could try football, too, but reminded him it would be very difficult for us to keep him cool under all that equipment.

He insisted he wanted to play, so we told him to go for it.

On the day of the first football practice, the weather was sunny, hot and almost unbearably humid. Kyle and his dad set off for practice with four gallons of water.

Kyle came home three hours later, totally soaked but with a smile on his face. "How was practice?" I asked.

Kyle replied that he had discovered football was not his sport. Mind you, he was smiling. For the first hour and a half, he had happily performed all the tasks the coach requested—sprints, monkey rolls and other drills. For the next half hour, he performed all the tasks the coach requested with tears in his eyes. And for the last hour, he sat on the sidelines, totally wet, watching the team.

That day, Kyle learned a lesson we all must learn at some point in life—there are some things we *can* do and there are other things we want to do, but can't. Kyle told me he was really glad he had tried to play football and that someday, when he is older, he will try again. But, he added, even if he doesn't ever play football, it's okay because he is good at basketball and baseball.

I am proud of Kyle because he tried his hardest to do something he wanted to do. I am proud of us, his parents, because we let him try. All in all, it turned out to be a great day. In my mind, Kyle is the star of that football team and always will be.

—Pam Spilbeler
Bloomington, Indiana

For more information about ED, contact The National Foundation for Ectodermal Dysplasias, 108 N. 1st St., Ste. 311, Mascoutah, IL 62258, (618) 566-2020.

More READERS' FORUM on page 100

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Best friends (from left) Robin Holmes, Mollie Hanson and Katie Baesemann enjoyed lunch at a Chicago restaurant during a day trip to the big city with their moms. They also took in a theater performance of *Joseph and the Amazing Technicolor Dreamcoat.*

What's in a Name?

One day recently, I was driving the eternal carpool to ballet with three teenagers in my back seat. All three girls have cognitive disabilities and have been in classes together since preschool. They enjoy adult interaction, in spite of the fact that they are teens, but I take a stance of "benign neglect" while driving, letting them sit in the back seat together and relate to each other. My ears perked up, however, when my daughter, Mollie, started talking about her syndrome. It came out of the blue.

"I have CVS [cyclic vomiting syndrome]," she announced and gave a sentence or two of explanation to her friends. "What do you have, Katie?"

After a moment to think and a bit of a prompt, Katie answered, "I have Williams syndrome." A few sentences of explanation followed with just a little assistance from me.

Then Mollie turned to Robin, who has Down syndrome. "What do you have, Robin?"

Robin's reply was immediate and despondent—"I have diarrhea!"

Luckily, I maintained control of the car as I squelched an enormous laugh. How lucky I was to be at the right place at the right time to hear this personal, matter-of-fact conversation. I again realized, in a vivid way, that much of the time, my daughter and her friends don't need labels or definitions. What they do need is ongoing care and concern in learning to deal with issues as they arise—the "issues of the moment." Robin's issues as a person living day-to-day far outweigh her need to have a named syndrome.

—Kathleen Adams
Elm Grove, Wisconsin

Cyclic Vomiting Syndrome (CVS) is a rare, unexplained disorder of children and some adults. The condition is characterized by recurrent, prolonged attacks of severe nausea and vomiting. Vomiting may occur five to six times an hour; an episode typically lasts one to four days. Mollie's cognitive disability is unrelated to CVS. For more information on CVS, contact the Cyclic Vomiting Syndrome Association, 13180 Caroline Ct., Elm Grove, WI 53122; (414) 784-6842, (414) 821-5494 (fax).

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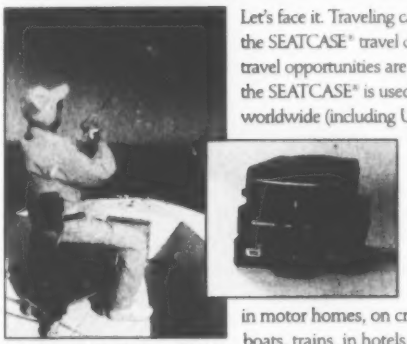

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Getting Off to a Good Start

Helping your child make the transition to a new school year

by Jeannie Lancaster

Jeannie Lancaster and son Sean look at a scrapbook containing pictures of the school Sean will attend the next fall.

It's only the beginning of summer, but fall—and the start of a new school year—will be here before we know it. For many children this means a move from elementary to middle school (or junior high), or from middle school to high school. These changes are exciting, but can also lead to anxiety and uncertainty. This is especially true for a child with special needs who has difficulty adjusting to change.

Our two sons, now 18 and 15, are both affected by fragile X syndrome. (For more about fragile X syndrome, see *Ask The Doctor*, page 117.) In spite of their common diagnosis, each boy handles change differently. Our youngest son's excitement over upcoming changes often results in hyperactivity and hand flapping. He is more social than his older brother and looks forward to new situations, but his physical behavior shows that he still feels apprehension. Our older son, who has a severe anxiety disorder, shies away from all new situations, panicking over the idea of new schedules, new teachers and new expectations.

Although the boys are very different in their approach to change, there are some things we have done through the years that have helped make transitions easier for both of them.

Things that have helped

• *Picture scrapbook:* I came upon this idea in an unusual place. I was reading a brochure from a moving company on ways to make moving to a new home easier for small children. One suggestion was to take pictures of the child's new home, city, schools and neighborhood, and place these pictures in a scrapbook for the child. Wow! I realized a scrapbook of this type might also be helpful for a child with special needs who was moving to a new school.

That spring, during the last few days of school, I headed off to the middle school my son would be attending in the fall, with camera in hand. I darted about the school taking pictures of teachers my son would have, the principal, the lunchroom, classrooms, the library and, yes, even the bathrooms. I'm sure there were a few people who thought I was a little crazy but it proved to be a good idea. Together, my son and I put together a scrapbook of pictures. During the summer we looked at the book and talked about the school.

• *Walking through the schedule:* Getting an advance copy of your child's schedule can also be helpful. Before school begins, you can try to set up a couple of times when you and your child can walk through the halls, learning the routes to and from classes. This will also allow the child to become accustomed to the school at a time that is free of excessive noise and other disruptions. Another idea—even more positive—would be to have an older peer, who will attend the same school, walk through the schedule with your child.

Getting together before school started helped both Sean and his earth science teacher, Tom Hewson, feel more comfortable about the coming year. The science department's pet iguana joined their meeting.

It's helpful to have the need for an early schedule written into your child's IEP (Individualized Education Plan). This year, our local high school announced a plan to hand out final schedules to all sophomores, juniors and seniors—all 1,300 of them—on the first day of school. But because our sons' IEP's specified that they be allowed to walk through their schedules before the start of school, we were able to get their schedules over the summer and avoid a potentially overwhelming situation.

• *Getting acquainted with teachers:* Advocating for our sons' inclusion in as many regular classes as possible has resulted in an increase in the number of teachers who serve them. This is especially true in middle school and high school. In an effort to help the teachers who will be working with our sons, we write notes introducing ourselves and our sons and send them to the teachers before school begins. We include information explaining fragile X syndrome and request a time when we could stop by to have our boys

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Stopping by to meet and greet members of the school administration is another good idea. Here Sean and his father, Dave, get acquainted with assistant principal Jana Frieler.

meet them. When we visit, we stay just long enough to say hello, shake hands and allow our boys to put a face with a name. This seems to make the transition on the first day of school a little easier. We've found most teachers to be extremely responsive to this approach and feel it has been a good start toward building a positive working relationship with them.

• *Other ideas:* Other things can be done to assist a child as he or she moves to a new school or begins a new school year. For example, make sure your child knows how the lunch program works in his or her school. Familiarizing the child with the bus schedule might also be helpful. Perhaps most important is for the parent to convey a positive attitude about school. These things don't take a lot of time, but they can make a big difference.

• *Keep in touch:* Too often, parents have contact with a child's school only when there are problems. It is also important to let teachers know when things are going well. Occasionally writing a note, thanking a teacher for the things that are working and letting them know you appreciate their efforts, can make a positive difference.

We cannot, nor should we, remove all obstacles in our children's lives. But there are some simple things we can do to make new situations less threatening and help the school year get off to a better start. This can be extremely beneficial for children who are challenged by anxiety in new situations. Some of these things take a little extra time, but the rewards far outweigh the sacrifices. **EP**

Jeannie Lancaster lives in Loveland, Colorado with her husband, Dave, and three children, Torri, David and Sean, all of whom have fragile X syndrome. Jeannie is a full-time student, part-time freelance writer and full-time advocate for her children's inclusion in all aspects of life. She has served on the board of directors of the National Fragile X Foundation and currently coordinates a local program called Loveland Oral Readers for Education (LORE) in which volunteers record books for students with reading delays.

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Interactive discussions are also planned with experts in metabolic diseases, the psychology of living with chronic disorders, genetic research, assistive technology and insurance reimbursement. Opportunities to meet other families coping with rare disorders will abound.

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Children's Health Notes

Cultural Resilience:
How Culture & Ethnicity Affect Health

How individuals think—their beliefs—influence the course of life events. For families and children living with chronic conditions, their beliefs can influence the meaning of the condition and shape the development of coping strategies.

These beliefs may even determine whether or not the family seeks medical help.

Still, little is known about the different cultural meanings of chronic illness and disability from the family's perspective. Researchers from the Center for Children with Chronic Illness and Disability collaborated with researchers at La Rabida Children's Hospital and Research Center and were awarded a grant to study the range of meaning that African, Hispanic, and European American families give to having a child with a chronic illness or disability.

The fact that families living in the United States in the 1990s are influenced by many cultures simultaneously make a multicultural approach preferable.

"What might be interpreted as cultural differences might really be a function of the family's economic situation or other circumstances," says Ann W. Garwick, Ph.D., researcher and clinician.

The purpose of the project is to:

- Identify the range of meanings that families give to having a child with a chronic illness or disability;
- Describe the impact of chronic conditions on families;
- Compare how families and primary care physicians view the impact of caring for a child with a chronic condition;
- Involve community leaders and members in the research project;
- Develop a theory and hypotheses on the influences of perceptions of childhood chronic illness and disability.

"One goal of this project is to better understand how culture influences a family's understanding of health, illness and disability so that health care providers can provide care that is culturally sensitive and pertinent to the needs of children and families from diverse backgrounds," Garwick says.

DEFINITION

Ethnicity
Group consciousness based on a sense of common origins, a sense of peoplehood.

DEFINITION

Culture...
Reflects the various differing values we place on our daily activities.

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Children's Health Notes

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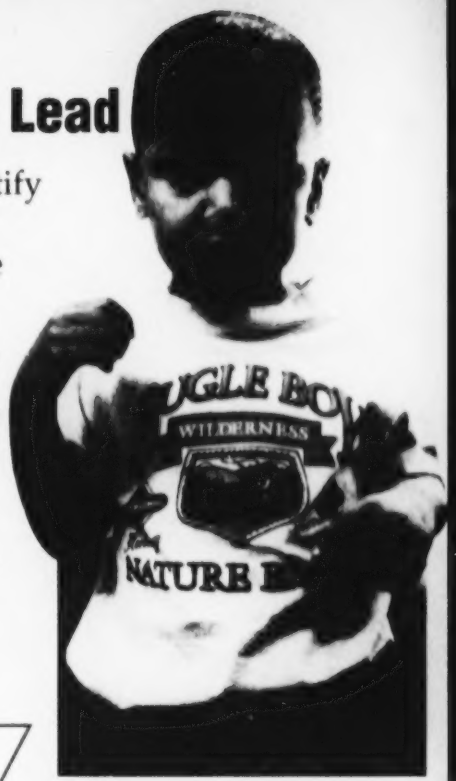
Communities Take the Lead



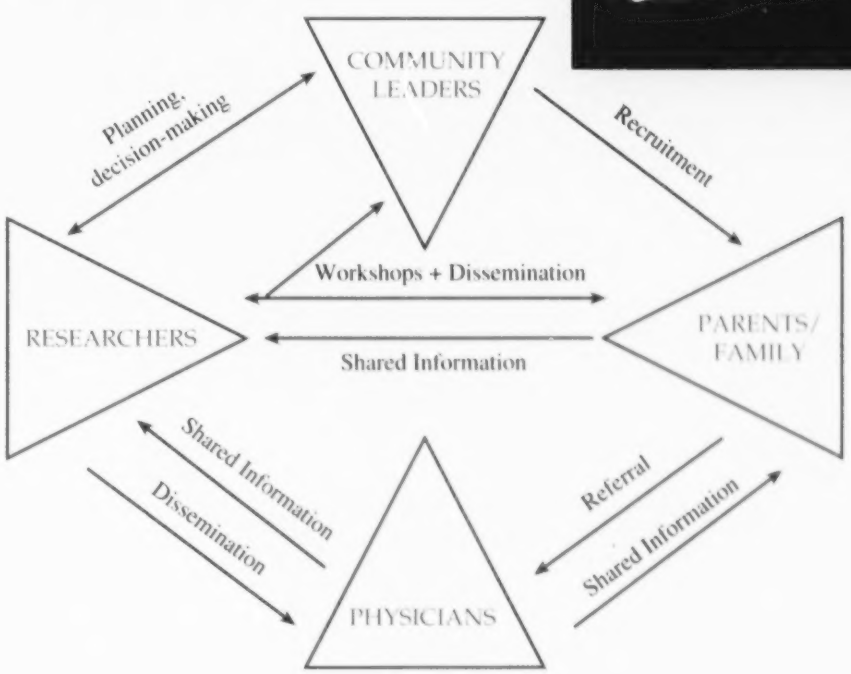
You'd think the easiest way to identify families to participate in this study would be to ask the doctors that see them.

That may be the easiest, but it may not be the best, especially when you're trying to clarify how cultural differences influence the way families understand their child's chronic illness and disabilities, especially when you want to be able to help health and education professionals work more effectively with children and families from diverse backgrounds.

So this project began by identifying

Community

Turn to page 106



Relationships Among Researchers & Participants

This diagram shows how researchers have established a collaborative relationship within the communities we are studying and reflects the complex web of relationships necessary to conduct research. Still, few arrows connect the families to the communities in which they live. Clearly, community agencies need to develop strategies to connect with families to decrease their isolation.

leaders in communities we wanted to study—African Americans, Hispanic Americans, and European Americans—to help us define, design, and pilot the study. And we asked them to help find willing participants. "What's interesting," Ann Garwick, one of the investigators, says, "is that while community leaders have been genuinely enthusiastic in reviewing questions and training (or becoming trained as interviewers), they had trouble finding families."

The leaders sought referrals from parents of children with disabilities through community groups such as boys and girls clubs, neighborhood community centers, parent support groups, religious groups, and YMCAs. And while they were able to recruit 58 for the study, recruitment has taken longer than expected.

...regardless of ethnicity and culture, families said they felt isolated...

Identifying children with disabilities and their families was challenging for the community leaders and took longer than the investigators planned. Given this experience, it should come as no surprise that early analysis of the interviews suggest that, uniformly and regardless of ethnicity and culture, many families said they felt isolated. Some say they feel this isolation because they have had to search so hard to find information on their child's condition or on the services available. Some feel that they have to advocate at every turn in their life. They say that programs don't exist in the community, rather, families have to ask for, and often start, appropriate programs. Still, some families report that they never see other families like themselves. Each of these signals that, while communities might be a wealth of support for some families, most community leaders and organizations are challenged when it comes to even identifying who, in their community, is raising a child with a chronic illness or disability.

With the interviewing complete, researchers have developed both the conceptual framework and the coding scheme for analyzing the family interviews. "Investigators at both sites have been reviewing the verbatim transcripts," Garwick says. Such analysis is time-consuming. Once the transcripts are coded, Garwick and her team review the material to identify what influences are specific to unique cultural perspectives.

How can we eliminate a family's sense of isolation?

Garwick says clear information should be provided not only to families but to the local churches, YMCAs, community centers, schools, day care programs and clinics. But that is just a start. Do you live in a community that has succeeded in integrating your child with a disability and your family in some way—large or small? What are some of the ways families feel less isolated, more connected to the community? Please let us know.

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When Physicians Talk to Parents:

Learning What Families and Physicians Share

Families know what they want and what they need. Regardless of ethnicity or culture, most families report they are satisfied when they feel they've been heard. They are satisfied when their concerns and ideas are valued and acted upon.

C3ID researchers are also interested in what physicians say and know about the impact of culture and ethnicity on the health of children with chronic illness and disabilities and their families. The physicians for each family involved in the project will be interviewed and will provide additional input.

A set of questions that would be appropriate for physicians was selected from the family interviews. The goal is to get at how physicians understand the family with a chronically ill child, their culture, support system and general coping process. Researchers will then compare the family and physician's points of view.

When we analyze the data, we are looking for recommendations that families and physicians have for improving care for children with chronic conditions from diverse cultural backgrounds.

"When we practiced the interview questions with physicians," Garwick says, "they felt the questions were clear and relevant." The questions themselves raise the physician's awareness of family and cultural issues. "Most are interested in getting feedback. One physician said, 'if you discover anything you think might impact on the way I interact with a family, or can help the family, please share it.'"

Physicians are also asked to complete scales similar to those to which families respond. The *Characteristics of Chronic Conditions Scale* includes questions about the child's type of chronic illness and treatment. This scale has been developed by a team of **C3ID** investigators. The questionnaire will provide data about chronic conditions that can be used to interpret issues and themes in family interviews that are related to the nature of the condition.

Like the families, physicians also respond to the "Impact on Family Scale." This scale tries to assess how a child with a chronic illness or disability affects a family. Does it cause financial problems? Have parents had to leave work? Take on extra work? Are they tired much of the time? Do

families feel closer? Both the physicians and the families indicate the degree to which they believe statements are true or not true. Physicians can also answer "don't know."

The **Center for Children with Chronic Illness and Disability** was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.

MISSION

The Center for Children with Chronic Illness and Disability is learning a great deal about children with chronic illness and disabilities, their families, and the political, health care, and policy environments that affect their care. To reach as many families as we can, we join with *Exceptional Parent* to publish *Children's Health Notes* to define the environment, raise questions, identify strategies, or provide clarification of issues that are critical to providing care for children with special needs and their families.

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Circle #140

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

The Katie Beckett Waiver

Q We own our own home, and our income puts us over the limit for Medicaid coverage. We have always raised our child at home, even though health care professionals have suggested institutionalization.

If our child was in an institution, the government would pay all the costs, including medical care. Since we have kept our child at home, however, the government will not pay for any of the costs. In fact, the government will not even pay for basic medical care. Is there anything we can do?

A Although the Medicaid regulations that apply to income limits seem quite rigid, there are some exceptions to those regulations. These exceptions are known as "waivers." Each waiver represents a situation in which specific states have applied for, and have been granted, exemptions from the standard Medicaid rules.

One of the most important of these Medicaid waivers is generally known as the "Katie Beckett waiver" or the "Katie Beckett provision." In the early 1980s, when the Katie Beckett waiver was first established, if a child with a disability lived at home, Medicaid generally considered parents' income in evaluating the child's eligibility. If the child was hospitalized or institutionalized for an extended period, however, the parents' income generally was not considered.

Katie Beckett, a young child who was on a ventilator, was unable to go home from the hospital, not because of medical reasons, but because she would no longer have been eligible for Medicaid. While Medicaid rules allowed for the continued payment of hospitalization costs, they did not allow Medicaid to pay for the cost of home care, even though home care would have been far less expensive.

Eventually, a special Medicaid waiver was created so that Katie Beckett could return home. Since that time, the Katie Beckett waiver has helped an enormous number of children who would have been forced by Medicaid regulations to remain permanently in hospitals or institutions.

State regulations

Since Medicaid is administered at the state level, the Katie Beckett waiver is available only to residents of those states that have adopted it. Although almost every state has some form of the Katie Beckett waiver, regulations may differ drastically from state to state. Contact your state Medicaid office to learn the details of your state's waiver.

According to the National Health Law Program, a child with a disability does not need to be institutionalized to qualify for the Katie Beckett waiver. Thus, depending on the state you live in, and the specifics of your child's disability, the waiver may be applicable to your situation.

The specific rules are complex. In general, however, the waiver may apply to a situation involving a child with a disability under 18 years of age, for whom home care is appropriate, and in which the child requires a level of care

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equivalent to that provided by an institution. In addition, the cost of home care must be less than or equal to the cost of institutionalization. The waiver is available only to children who would qualify for Medicaid if institutionalized. There are other specific rules, as well.

In states that have not adopted the Katie Beckett waiver, Medicaid will consider paying the costs of long-term institutionalization for a child with a disability, regardless of the parents' income. However, even though the state would have to pay the full costs if the child were institutionalized, those state Medicaid programs generally will not pay any medical costs for a child with a disability if he or she is being cared for at home, unless the parents' income meets Medicaid eligibility requirements.

If denied

If your Medicaid application has been denied, and you think you qualify under a Katie Beckett waiver or under a different waiver program, contact your local Protection and Advocacy office or the local legal services office for advice. For your local offices, contact the National Legal Aid and Defense Association, 1625 K St., NW, Ste. 800, (202) 452-0620 (voice), (202) 872-1031 (fax).

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, *209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).*

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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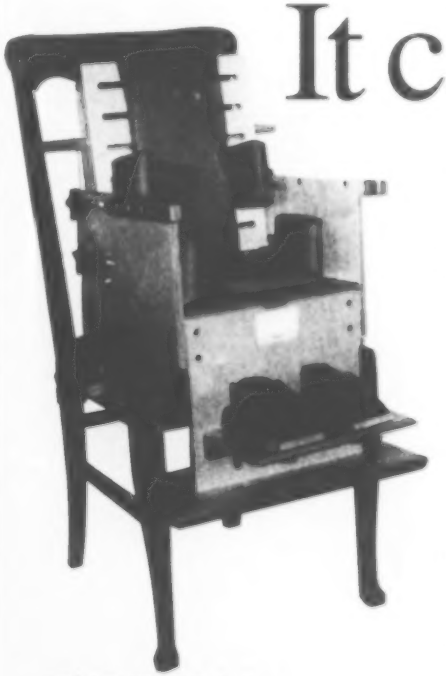

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Irene Pollin, author of TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS, *is a parent and psychiatric social worker. In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope with long-term effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed.*

Although TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS *was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members. Here's what nationally-syndicated columnist Ann Landers says about* TAKING CHARGE: *"[This] book... should be required reading for everyone facing the challenge of long-term illness, whether their own or that of a loved one... It could be the most valuable gift you will ever give."*

In Pollin's words—"I have discovered that by confronting and taking charge of your fears, you can learn to accept your [or your loved one's] long-term condition. Indeed, you can once again take charge of your life." TAKING CHARGE *is available from Exceptional Parent Library (800/535-1910). The following is an excerpt:*

Face Your Fears

Many people worry that if they confront their fears, they'll fall apart or lose control. In truth, all of us wish to be secure in what we know we can count on. It feels safe and reassuring to have a sense of control. However, it doesn't follow automatically that if you're frightened or unsure of what's in store you'll be out of control.

Every day, uncertainty slips into our lives. Neither a salesperson nor a department store buyer knows in advance how many items they'll sell, yet they order merchandise. A restaurateur shops for and prepares meals by predicting how many patrons will order roast beef or fish or lasagne in a given evening—but he never knows for sure. There is an expectation of certainty, but in fact no one is certain the expectation will be fulfilled.

While we can conduct business tolerating a measure of ambiguity, we find it hard to apply these principles to our health. We want to be sure we are healthy yet we can never really be completely confident. What goes on within our bodies is often invisible to us. We don't recognize a problem until it becomes a bleeding ulcer or shortness of breath. In truth, we live with uncertainty all the time, yet we maintain control of our lives.

Nevertheless, "fear of falling apart" pushes people to keep their other anxieties inside, even when it means going against their natural tendency to face them and express themselves openly. For example, Emily, one of my young patients from Chicago, became uncharacteristically silent after a diagnosis of multiple sclerosis. Her husband felt so uncomfortable with her atypical demeanor that he finally screamed at her, "For God's sake, Emily, you've got MS. Where's your reaction?"

All her life, Emily had prided herself on her ability to communicate. Now, however, she feared losing control if she verbalized her terrifying thoughts: "Will I end up in a wheelchair?" "Will I be able to have children?" "If I do have kids, will they have to care for me or make the decision to put me in a nursing home?" Once she allowed herself to voice these terrible but understandable fears to herself and her husband, not only did she feel more stable emotionally, but she was able to make decisions about her life that eased her adjustment to her new situation...

You [can] face and resolve your fears by examining the most salient ones in detail. One fear—what I like to call the "ninth fear"—asserts that you're making up all the others. This attitude can undermine your ability to accept your other anxieties as legitimate. When you succumb to it, you don't permit yourself to be serious about or respectful of your own needs.

Let me assure you that even though in the past some of your fears may have been unfounded, today they are valid. They're based on real problems. If you're anxious that a surgical procedure is dangerous, it probably is. If you're worried about the long-term side effects of a medication, you probably have good reason. In fact, as you make your own medical decisions, you'd be remiss if you didn't consider the consequences carefully. Your worries, therefore, aren't imaginary. They are compelling and should never be dismissed.

Some people fear that their feelings during this vulnerable time are "irrational." In truth, emotions are never rational or logical—they're emotions. Moreover, given the high state of anxiety that chronic illness provokes, it seems perfectly normal to feel irrational at this time. Emotions and actions are distinct, however. Feeling irrational does not mean that you'll act irrationally.

A final note: It's important to recognize that your worst fear may never come true. Since the course of most chronic illnesses is unpredictable, your situation could improve rather than worsen, as in the case of one distraught woman who had checked into the hospital to undergo risky surgery for the removal of a tumor in her neck. During the final pre-operative exam, her surgeon discovered that the tumor had shrunk and surgery was no longer necessary. Until that moment, it had never occurred to this woman that she would be spared the operation!

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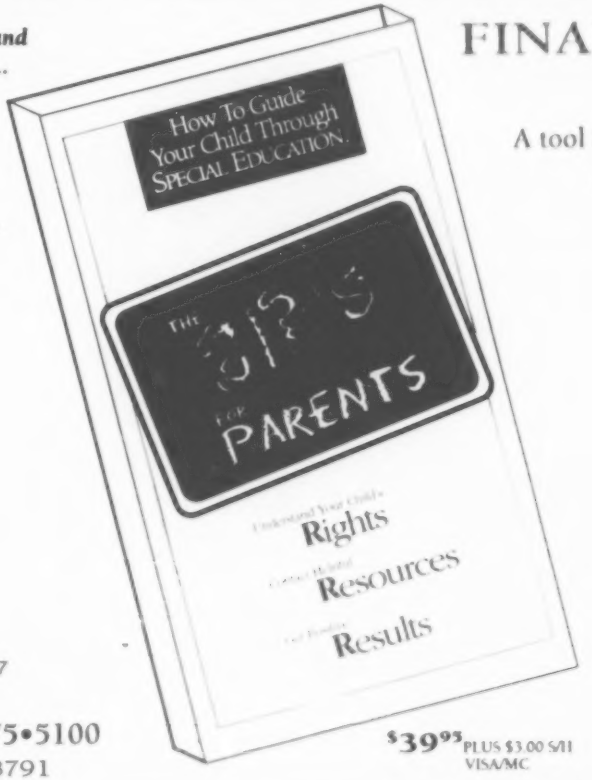

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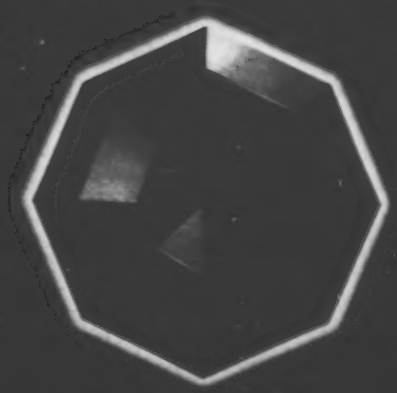

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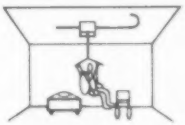

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Patricia McGill Smith
Executive Director

Holding young reception attendee Allyson Sparks, Sen. Bill Frist, R-TN, chairman of the Senate's Disability Policy Subcommittee, reaffirms his commitment to people with disabilities at NPND's second annual congressional reception.

NPND Congressional Reception

The National Parent Network on Disabilities (NPND) held its second annual congressional reception March 13 to honor parents of children with disabilities. Senate Majority Leader Bob Dole, R-KS, sponsored the event.

Sen. Bill Frist, R-TN, chairman of the Disability Policy Subcommittee of the Senate Labor and Human Resources Committee, reaffirmed his commitment to work with families to improve programs for people with disabilities. He extended an invitation for people to participate on his team, and to work with him during these challenging times.

Other legislators attending the reception included Sens. Nancy Kassebaum, R-KS; Tom Harkin, D-IA; Paul Wellstone, D-MN; and Christopher Dodd, D-CT; and Reps. William Goodling, R-PA; Major Owens, D-NY; Steny Hoyer, D-MD; George Miller, D-CA; and David Hobson, R-OH.

Also during the reception, NPND's Distinguished Service Award was given to Diana Cuthbertson, former president of NPND's board of directors. Cuthbertson was recognized for her tireless work on behalf of parents and children with disabilities.

NPND thanks the organizations and individuals who helped make this reception a success: Parent Training and Information Centers, members of the Consortium for Citizens With Disabilities and the individual NPND members who contributed financial support for the event.

Legislative Update

With its first 100 days behind it, Congress took a recess beginning mid-April. It left behind a trail of legislative setbacks and attacks on people with disabilities. Upon its return, this assault on the rights of people with disabilities was expected to continue.

SSI Children's Benefits

The House of Representatives passed the Personal Responsibility Act (PRA), a bill with provisions that would save federal dollars by eliminating 250,000 children from the SSI (Supplemental Security Income) program, which provides funds to people with low incomes and limited assets who are 65 or older or who have disabilities. If PRA is passed by the full Congress, the savings will be passed on to the states as block grants. Children and adults who lose their federally-administered SSI benefits

continued on page 116

NPND executive director Patricia McGill Smith (left) presents Diana Cuthbertson, past president of NPND's board of directors, with the NPND Distinguished Service Award at the congressional reception. In the foreground are Joanne Butts, NPND president, and Cuthbertson's husband, Hank.

Volunteers Needed for Media "Swat Team"

NPND, in conjunction with other disability advocacy organizations, is forming a national Media Swat Team. This team will keep track of reports in the media that are damaging to people with disabilities and issue replies as swiftly as possible. If you are interested in volunteering as a media monitor or writer, contact Larry Searcy, NPND, 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

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continued from page 115

can apply to their states and may receive benefits that each state decides to provide.

Under PRA, those not eliminated will continue to receive cash payments from the federal government as long as they qualify. However, cash payments will be phased out because all new SSI applicants will have to apply to their states.

The House bill also eliminates the "individual entitlement" component of SSI benefits. This means that even if a child is deemed "eligible" for benefits, the child will not be "entitled" to receive services. Waiting lists for recipients will be developed and services will be delivered on a first-come-first-served basis.

NPND had been told that the Senate is likely to uphold the provisions of the House bill. As *Exceptional Parent* went to press, however, NPND had just been told that Sen. Kent Conrad, D-ND, was expected to introduce a Senate alternative to the House approach that would be much more favorable to children. Details were not known as of press time.

Reauthorization of IDEA

As *Exceptional Parent* went to press, the Senate leadership was pressing for a one-year extension of the Individuals with Disabilities Education Act (IDEA) to ensure that none of IDEA's funds would expire at the end of this fiscal year, September 30.

The Senate had planned hearings on IDEA for May 9, 11 and 16. In June, the Senate intends to hold staff briefings on IDEA for staffers of the Senate's Disability Policy Subcommittee. According to the Senate calendar, a draft bill will be produced in August or September. Hearings will then be held on the draft bill with floor action expected in October or November.

The House had planned to participate in a joint hearing with the Senate on May 9 and was to hold its own hearings May 16. House staff have indicated that they will aim to produce a draft bill by early summer with floor action by the end of September.

Heritage Foundation Calls For Elimination of Education Department

The Heritage Foundation, a leading conservative think tank, has called for the elimination of nine presidential, cabinet-level departments. According to an April 17 press release, the group has proposed reducing the number of such departments from 14 to five. Some would be consolidated, others would be reduced to sub-cabinet independent agencies, while others would be completely eliminated with responsibilities shifted to states.

NPND is concerned because the group has proposed closing down the Department of Education, "though some of [its] functions, as part of the overall streamlining and consolidation process, would be shifted to the states or moved elsewhere within the federal government." The group has not indicated what would happen to special education programs under this proposal.

Ed Roberts 1939–1995

Ed Roberts, the father of the independent living movement for people with disabilities, died in March at his home in Berkeley, California. He was 56.

We have lost one of the greatest leaders of our time. Ed was a monumental role model, teacher and advocate for parents and children with disabilities.

As a result of polio at the age of 14, Ed was paralyzed from the neck down and left with motion in only one finger. He was ventilator-dependent, and slept in an iron lung. Ed was the first student with severe disabilities to attend the University of California at Berkeley.

In 1972, Ed co-founded the Center for Independent Living (CIL) in Berkeley. CIL became a model for more than 400 similar centers worldwide run by and for people with disabilities. Ed went on to head California's State Department of Rehabilitation and to co-found the World Institute on Disability, a public policy, research and training organization, with Judy Heumann. In 1984, Ed received a prestigious MacArthur Foundation "genius" award.

Recognizing Ed's loss, Pres. Clinton eulogized: "As an international leader and educator in the independent living and disability rights movements, he fought throughout his life to enable all persons with disabilities to fully participate in mainstream society... Mr. Roberts was truly a pioneer... His vision and ability to bring people together should be an example for everyone."

"We Have Promises To Keep" Rally

On June 22, NPND, along with the Spina Bifida Association of America and other disability organizations, will stage a rally on the West Steps of the U.S. Capitol Building in Washington, DC. The rally will be held from noon to 2 p.m. Speakers will include lawmakers and leading national disability advocates. Entertainment and refreshments will be provided. After the rally, participants are being urged to lobby their senators and representatives.

Members of Congress often say they are do not hear from the disability community. Let's make a statement that they won't soon forget. For more information, contact NPND, 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

Join the Family Action Network (FAN)

Please complete and return this form to NPND to join FAN. FAN Alerts and newsletters about important legislation and other information will start arriving as soon as your subscription is received by NPND.

This is most important as IDEA is up for re-authorization. FAN members will receive quarterly newsletters with updates on how IDEA is faring in Congress. Alerts of timely information and requests to take action to save IDEA will be sent when necessary.

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ASK THE DOCTOR

by David Hirsch, M.D.

Fragile X Syndrome

Q Our son is seven years old. We know he is mentally retarded and, according to his pediatrician, he has some features of fragile X syndrome. He has had a number of diagnostic tests, including chromosome tests. All have been "negative." Our family has no history of mental retardation or any other genetic diseases. We do not want our son to go through any unnecessary testing. Do you have any suggestions? If he does have fragile X, is there anything else that can be done?

A Fragile X syndrome is the most common cause of inherited mental retardation. It occurs in approximately one in 1200 males and one in 2500 females.

Fragile X syndrome is called an "X-linked disorder" because the FMR-1 gene, the gene responsible for fragile X syndrome, is located on the X chromosome (one of the sex chromosomes; the other is the Y chromosome which only males carry). A woman who carries the gene for an X-linked condition has a 50-50 chance of passing it to either a son or daughter, since she contributes one of her two X chromosomes to each child. A man with the same X-linked gene passes it to all his daughters (they all receive his X chromosome) and none of his sons (they all receive his Y chromosome).

The severity of fragile X syndrome in an affected individual is usually related to the size of the DNA mutation within the FMR-1 gene. Some intellectually normal people have a fragile X "premutation," or small mutation. These premutations are unstable and can expand in size when passed from mother to child. If the premutation expands to the size of a full mutation, the FMR-1 gene "turns off" and does not work properly. Of the females who carry a fragile X mutation, approximately 33 percent will show some symptoms; in males with the mutation gene, roughly 80 percent will have some degree of learning and behavioral problems.

Common physical characteristics of fragile X syndrome may include a long, narrow face; prominent forehead; prominent, square chin; large ears; a flattened nasal bridge; a high, arched palate (roof of mouth); a relatively large head and large testicles. These facial features tend to be more noticeable in adults than in children, and in males more often than females. Many children with fragile X who are younger than six do not differ greatly in appearance from other children.

Males with fragile X syndrome usually have mental retardation varying from mild to severe, with the majority of affected males within the moderate range of intellectual disability. The vast majority of individuals with fragile X, especially males, will have developmental delays (most commonly speech delays), poor gross motor coordination and, sometimes, autistic-like behavior.

Your son may have some or all of these characteristics to a varying degree, but a definitive diagnosis of fragile X syndrome can only be made by more sophisticated genetic testing, specifically "direct DNA analysis" that looks for the presence of a very specific piece of DNA within the FMR-1 gene. It is very possible that the routine chromosome tests already done on your son (sometimes called cytogenetic testing) might not detect fragile X syndrome. Direct DNA analysis is done with a small sample of blood sent to a lab that has expertise in this area of genetic testing.

I certainly agree that your son should not have any unnecessary testing. However, if he does have some typical physical features and/or behavioral characteristics of fragile X syndrome and the cause of his mental retardation is not yet known, even with the negative family history, I believe it would be worthwhile to have a comprehensive genetic evaluation and appropriate DNA testing done. When a definitive diagnosis is obtained, it is easier to plan for a child's future, design appropriate educational programs and find parental support groups. The blood test should not be very painful, however, the cost may be significant.

No medication or other treatment has been shown to be absolutely effective for individuals with fragile X syndrome. Folic acid supplementation has been tried, but I do not believe there is any clear evidence regarding its effectiveness. Speech, occupational and physical therapy, as well as the most appropriate educational environment, would be required to assure your son's optimal development.

For more information about fragile X syndrome contact FraXa Research Foundation (P.O. Box 935, West Newbury, MA 01985; 508/462-1990; e-mail: fraxa@destek.net) or National Fragile X Foundation (1441 York St., Ste. 215, Denver, CO 80206; 800/688-8765, 303/333-4369, fax). **EP**

In this column, David Hirsch, M.D., a pediatrician and member of the EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch mentions specific products or medications only to illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-5742 (Fax).

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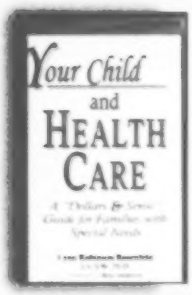

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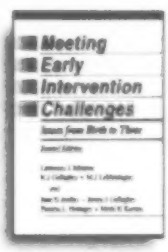

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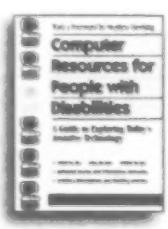

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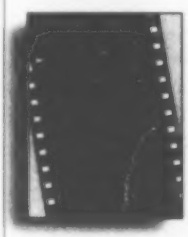

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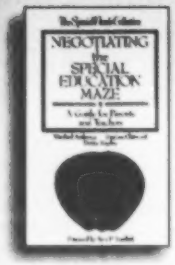

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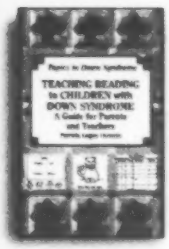

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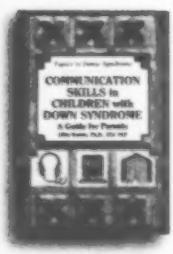

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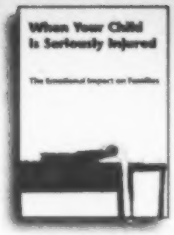

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Obtaining regular employment and a driver's license, learning to play the piano and organ, marriage and independent living—these are just a few of the milestones we see achieved in this hopeful video. Order from: Utah Down Syndrome Foundation, Southern Utah Chapter, 1035 E. 100 South, St. George, UT 84770; 800-773-0437; $15, includes postage. Proceeds benefit the Utah Down Syndrome Foundation.

Off to College

The HEATH Resource Center offers brochures and papers about postsecondary education for students with disabilities:

• *Getting Ready for College: Advising Students with Learning Disabilities* offers information for students and student advisers. The paper discusses disability awareness, transition and assessment, arranging for special administration of college entrance exams and contacting campus disability officials before applying.

• *1995 Financial Aid for Students with Disabilities* provides information on scholarships and other resources. The paper gives advice on filling out financial aid forms and computing disability-related expenses, and lists organizations providing scholarships specifically for students with disabilities.

• *The Americans with Disabilities Act (ADA): The Law and Its Impact on Postsecondary Education* describes the law and the rights of students. When requesting this brochure, ask also for *Section 504: The Law and Its Impact on Postsecondary Education.*

For free single copies of any of these publications, contact HEATH Resource Center, One Dupont Cir., Ste. 800, Washington, DC 20036; (800) 544-3284 (V/TTY), (202) 939-9320 (V/TTY).

Essay Contest for Children

The National Association for Medical Equipment Services (NAMES) is conducting "There's No Place Like Home," an essay contest in which children aged 8–13 can point out the benefits of home care using home medical equipment services. To enter the contest, a child should write a letter to Pres. Bill Clinton on the following: "In 100 words or less, explain why you are glad home medical equipment services or rehabilitation/assistive technology allows you or your relative to be cared for at home rahter than at a hospital. Why do you like it better? If you are writing about a relative, why do you think he or she likes it better?" First place state/ regional winners will receive a $100 savings bond and compete for the national prize—a $500 savings bond and two-day all-expenses-paid family trip to Washington, DC. Local and national runners-up will also receive prizes.

Send essays to Deidre Moore, Manager of Communications, NAMES, 625 Slaters Ln., Ste. 200, Alexandria, VA 22314-1171. All entries must be received by July 17, 1995. For more information, call (703) 836-6263.

Support Groups

• The National Spinal Cord Injury Association (NSCIA) has started the free In Touch With Kids (ITWK) program to help children and youth under the age of 18 with ***spinal cord injuries*** connect with each other. ITWK members receive NSCIA's quarterly newsletter and the *Pen Pal Partners Catalog* with names and addresses of other kids around the world. Contact NSCIA, 545 Concord Ave., Ste. 29, Cambridge, MA 02138; (617) 441-8500, (617) 441-3449 (fax).

• The Biliary Atresia and Liver Transplant Network provides a support network for families of children born with ***biliary atresia*** (both pre- and post-liver transplant). For more information, contact Biliary Atresia and Liver Transplant Network, 3835 Richmond Ave., Staten Island, NY 10306; e-mail: OrganTrans@aol.com.

Help for Parents of Children with ADHD

Understanding the ADHD Child: Information for Parents About Attention Deficit Hyperactivity Disorder is a new booklet available from the American Academy of Pediatrics (AAP). The booklet defines ADHD, and explains its symptoms and causes. The booklet also covers diagnosis, treatment and educational concerns. To order, send a self-addressed, stamped, business-size envelope to AAP, Dept. C, Understanding the ADHD Child, P.O. Box 927, Elk Grove Village, IL 60009-0927; free.

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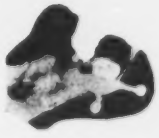

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EXCEPTIONAL PARENT

June 1995

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Facility _____

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_____

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Phone _____ Fax _____

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ☐ Yes ☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ☐ Yes ☐ No

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D. Are you an EDUCATOR? ☐ Yes ☐ No

If Yes, are you a: ☐ Special Ed Teacher ☐ Regular Ed Teacher ☐ Admin/Dir ☐ Other (please indicate) _____

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ☐ Yes ☐ No

If yes, please explain _____

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F. Have you ever bought or recommended a product or service you saw advertised in *Exceptional Parent*? ☐ Yes ☐ No

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If yes, please explain _____

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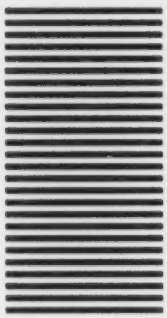

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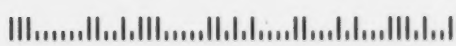

NEW PRODUCTS

SELF-FEEDING PLATES

The Inner-Lip Plate and the Round-Up Plate help children feed themselves by preventing food from sliding off the plate. Each plate includes three legs and suction cups that raise it one-quarter inch off the table, and when moistened, secure the plate to virtually any surface. The Inner-Lip Plate features a wide rim around the plate's circumference, while the Round-Up Plate has a narrow rim on one side and a wider rim on the other.

Maddak, Inc., Pequannock, NJ 07440-1993

Circle # 195

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This chair provides correct orthopedic support. A single mechanism allows easy tilt in space and the height can be adjusted for dinner table or classroom desk use. Features adjust without tools to easily accommodate growth and special needs. Custom sizes and modifications available.

Adaptive Design Labs, West Orange, NJ 07052

Circle # 196

METRO BASIC BUGGY

The Metro Basic Buggy (Model 3M) is a stroller that provides basic transportation for children ages 5 to 12 or weighing up to 125 pounds. The buggy features a lightweight aluminum-and-flexible-steel folding frame. A sling seat with an integrated trunk stabilizer provides proper seating and positioning. Equipped with toggle brakes for safety.

Convaid Products, Inc., Ranch Palos Verdes, CA 90274

Circle # 197

EASY ACCESS SHOWER STALL

The Easy Access Shower Stall provides a roll-in wheelchair-accessible shower stall in the space of a standard bathtub. The design offers tool-free installation. Available in four- or seven-piece units, each piece locks in position as it is set in place. The leak-proof seams require no caulking. A variety of colors and accessory packages are available.

SafeTek International, Inc., West Melbourne, FL 32901

Circle # 198

WUMBRELLA

The Wumbrella (Wheelchair Umbrella) eliminates the need for hats and unwieldy hand-held umbrellas. The removable convertible canopy mounts on the handlebars of most wheelchairs using Velcro and does not interfere with regular wheelchair use. When not in use, the device collapses below the handlebars or can be removed for storage. Available in a variety of colors.

Osprey Engineering, Winchester, MA 01890

Circle # 199

BIG-HUG & LITTLE-HUG VERTICAL STANDER

Both of these standers feature height-adjustable chest and pelvic straps and knee pads and foot restraints. The reversible frames allow children to be fitted from the front or rear. The frame detaches from the baseboard for transport and storage. The Big-Hug accommodates children who are 40 to 52 inches tall, while the Little-Hug fits children from 30 to 42 inches.

Tumble Forms, Jackson, MI 49204-0089

Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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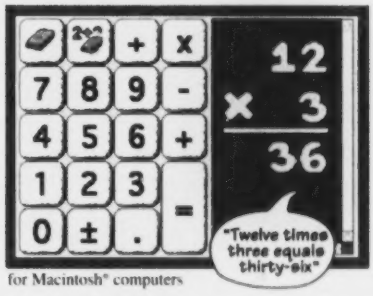

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Circle #141

RESEARCH

The Special Parents Project

A survival guide for new parents

by Bruce Robinson and Lorna Catford

Bruce Robinson and Lorna Catford are pictured here with daughters Amber, 4, and Naomi, 2.

The birth of our two-year-old daughter, Naomi, inspired the creation of the Special Parents Project. Her condition—an undiagnosed neuromuscular disorder and profound developmental delay—led us to re-examine our professional priorities (Dad is a writer and Mom is a psychotherapist and educator). Now we are pursuing our new dream of providing a caring guide for others who unexpectedly share our abrupt and disorienting journey.

When we were told, "Naomi's not OK," we didn't know where to turn. We knew no one in the special needs community. We didn't have a clue about how to deal with the medical and insurance system, nor did we know any of the resources that might be available to us. We felt painfully alone with our shattered dreams.

We searched libraries and bookstores. We found books about specific diagnoses, but nothing to give us the support we needed right then, when we were dealing with the initial grief, panic, immobilization and disbelief.

Writing the book we couldn't find

Now, we have set out to write the book that we couldn't find. The first step was the creation of a set of questions for other parents to answer about those difficult first months after a child with a complicated medical situation is born. Our questionnaire addresses subjects such as family and sibling relationships, financial impact of a child's disability and sources of interpersonal and emotional support.

The responses from this survey will be compiled and published in a "survival guide" for new parents, to offer them empathy, support and ideas for making it through the pain and adjustment of the first year. A pilot project has already been completed in association with California State University at Sonoma. We will report on our work and publish excerpts in future issues of *Exceptional Parent*. In conjunction with the book, the Special Parents Project will also establish a support network for parents and work to boost public and legislative awareness of disability issues. In addition to your survey responses, we welcome any referrals or ideas for funding our project.

As we head into the third year of our own special parenthood, we are learning to balance the demands of dual careers, the needs of Naomi and big sister Amber, 4, domestic chores and our effort to extend care and connection to the courageous and overwhelmed souls feeling their way along this unplanned path.

Your participation is invited

You are invited to participate in a study of the experiences of parents whose infants are critically ill or have other special needs. Please respond to each question (see next page) in as much detail as you wish. You may answer just those questions that seem most important to you. Please indicate the number of each question to which you are responding.

You can write or type answers on a separate sheet of paper or record your answers on a cassette tape if that is easier than writing or typing. You can also send your responses on a 3.5" Macintosh- or IBM-formatted computer disk (saved as a "text" or ASCII file) or by e-mail to lorna.catford@sonoma.edu.

- Give specific instances when possible.
- Share tips that might be helpful to others.
- Short answers are fine; we'd prefer short answers to not hearing from you at all.
- Fathers are especially encouraged to respond. **EP**

583

A: Background

1. Your name, address, and phone number. (Optional) May we use your real names?

2. Who are the members of your family (names, ages, relation to you)? Which family members have special needs?

B: Discovery

3. How did you first know something was wrong?

4. What is your child's diagnosis or disability?

5. How were you informed? Who told you? In what setting? Who was there?

6. What were your reactions? What did you feel? What did you do? Were you referred to any support services?

C: The Emotional Roller Coaster

7. How have your feelings evolved since finding out about your child's disability?

8. How have your values, priorities, world view or religious faith been affected?

9. What are your greatest fears? How do you deal with them?

10. What is the worst thing that has happened? How did you handle it?

11. What do you do to take care of yourself?

12. What truths or personal strengths have you discovered?

D: Relationships

13. What has happened to your relationship with your mate? Do you have any advice for other couples?

14. How do you meet your other children's needs? How do they and their "special" brother or sister relate?

15. In what ways have grandparents, other family members and friends been supportive or problematic?

16. If you are a single parent, what are the needs and issues that are specific to the absence of a partner?

17. What opportunities have you found for networking with other special parents? What has been most valuable or useful about those contacts?

E: Facing the World

18. Describe the daily routine with your child. What's hard? What's become easier? What helps?

19. How do you get doctors, insurance companies, agencies and medical bureaucrats to take your concerns seriously?

20. How has your child's condition affected your financial situation? Your work? How are you coping?

21. Recall instances in which you had to handle strangers' reactions to your child. What did you do?

F: Heavy Issues

22. Have you at any time had to deal with your own disability or serious illness while caring for your child? How did you manage?

23. If you have lost your child, what was that like for you? How did you cope?

24. Have you considered placing your child in out-of-home care? What has that been like for you?

G: Final Thoughts

25. What books, publications or groups have been most helpful for you?

26. What ideas can you share for dealing with specific issues raised in earlier questions?

27. What healing advice can you give other parents regarding picking up the pieces of shattered dreams?

28. Do we have your permission to use your name and the other names you mention in any published materials based on this survey?

29. Would you like to communicate with other parents as part of a support network related to this project?

If you would like to send us copies of any of your art, poetry or journal entries relating to your experiences with your special child, we would love to see them. Send them along with your responses to the questions to: Bruce Robinson and Lorna Catford Ph.D., The Special Parents Project, 5954 Van Keppel Rd., Forestville, CA 95436, (707) 887-2154. Our Internet address is lorna.catford@sonoma.edu.

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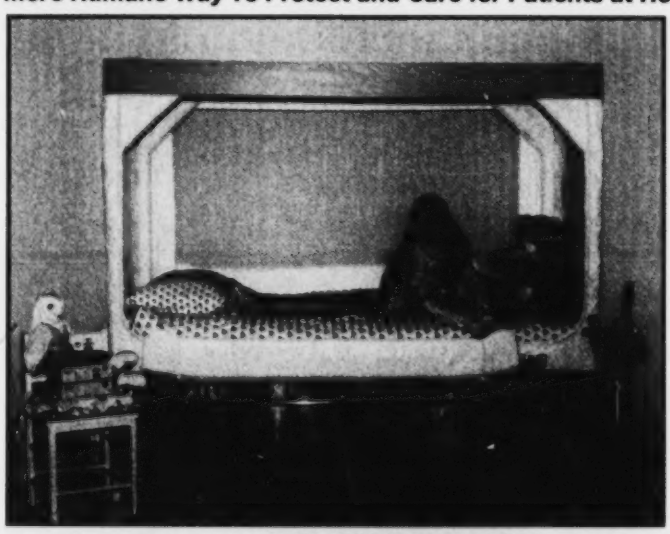

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Circle #33

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CHILDREN'S PAGE

PLAY BALL!

by Serena Cucco

Back when I was in second grade, I began going to my dad's coed softball games. It was there that I got interested in baseball. Mom and the other players gave me the play-by-play so I could follow the game. The players had high spirits. Coach would bang his glove on the bench and yell, "Defense! Defense! Let's get those outs!" The men would yell and holler, especially if there were controversial calls. I even heard some *bad language* being uttered from their mouths! Baseball seemed like an exciting sport.

One day, Daddy called Mom from work and said, "Get your sneakers on. We need one more woman to play tonight or else we have to forfeit." Mom didn't really want to play because she had no experience, but she didn't want the team to have to forfeit, so she got her sneakers on and went to the field. Mommy wasn't exactly the best player the ball club had ever seen, but her being there allowed the team to play for the rest of the season.

While visiting blind sports commentator Don Wardlow in July, Serena met and interviewed Patrick Lennon of the New Britain Red Sox. Serena's interview with Lennon was played on the pregame show and published in *USA Today Baseball Weekly.*

By now, three-quarters of my family were playing baseball. My mom and dad were playing once a week and my brother was playing T-ball on Saturday mornings. There was only one quarter left not playing—me! I decided I wanted to play T-ball too. I got ready by swinging my Thunder Bat 25 times a day.

The next season, I joined my town's T-ball league. My brother and I were on the same team. I got a lot of good base hits. I ran the bases and took the field with a coach.

I started to listen to professional baseball on the radio. My favorite team was—and still is—the Mets. (Go Mets!) Listening to the games helped me decide I want to become a sports announcer when I grow up. A sportswriter friend of our family arranged for me to meet color commentator Don Wardlow at work as the New Britain Red Sox took on the Trenton Thunder. It just so happens that Don Wardlow is blind and so am I! I spent an action-packed day with Don, his partner Jim Lucas and Gizmo the Wonder Dog, Don's guide dog.

Nowadays, my sport is kickball. I play every day at recess with the fifth and sixth graders. We adapt the game by having somebody stop the ball with her foot in front of my foot. Then I kick. I run the bases and take the field with a teammate. The teachers say "nice try" to all the players, no matter what team they are on. I'm more competitive than that—I only root for my own team!

Next year, I plan to play girl's softball in the town league. I'm looking forward to a great season. **EP**

Serena Cucco is 11 years old. She lives in Madison, New Jersey with her parents, Bill and Carol, and her younger brother, John, 8. Serena is a fourth-grader at Kings Road School in Madison, where she especially enjoys writing workshop, science, spelling, football and recess.

Mom's turn:

Although I never thought any girl child of mine would end up being a sports fanatic, I find myself living with a daughter who can tell you what happened in the first game of the NFL playoffs three years ago. Many people are surprised to learn that Serena enjoys "watching" sports; they are even more surprised that she participates. Sports is just another area of life in which the general public assumes blind people cannot be involved.

But we began learning a valuable lesson when Serena was just a baby—that there's almost always a way to get a blind kid into the game, whether a sports game or the game of life. We have made it a point to get to know lots of blind adults, many of whom hold jobs most people would assume are impossible for a blind person to do. We're determined to keep all the doors open for Serena; we thank these adults and the National Federation of the Blind for inspiring us to do just that.

—Carol Castellan

Batter up! Serena suited up last April for a game in the Madison Little League.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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EXCEPTIONAL PARENT

The Magazine for Families and Professionals

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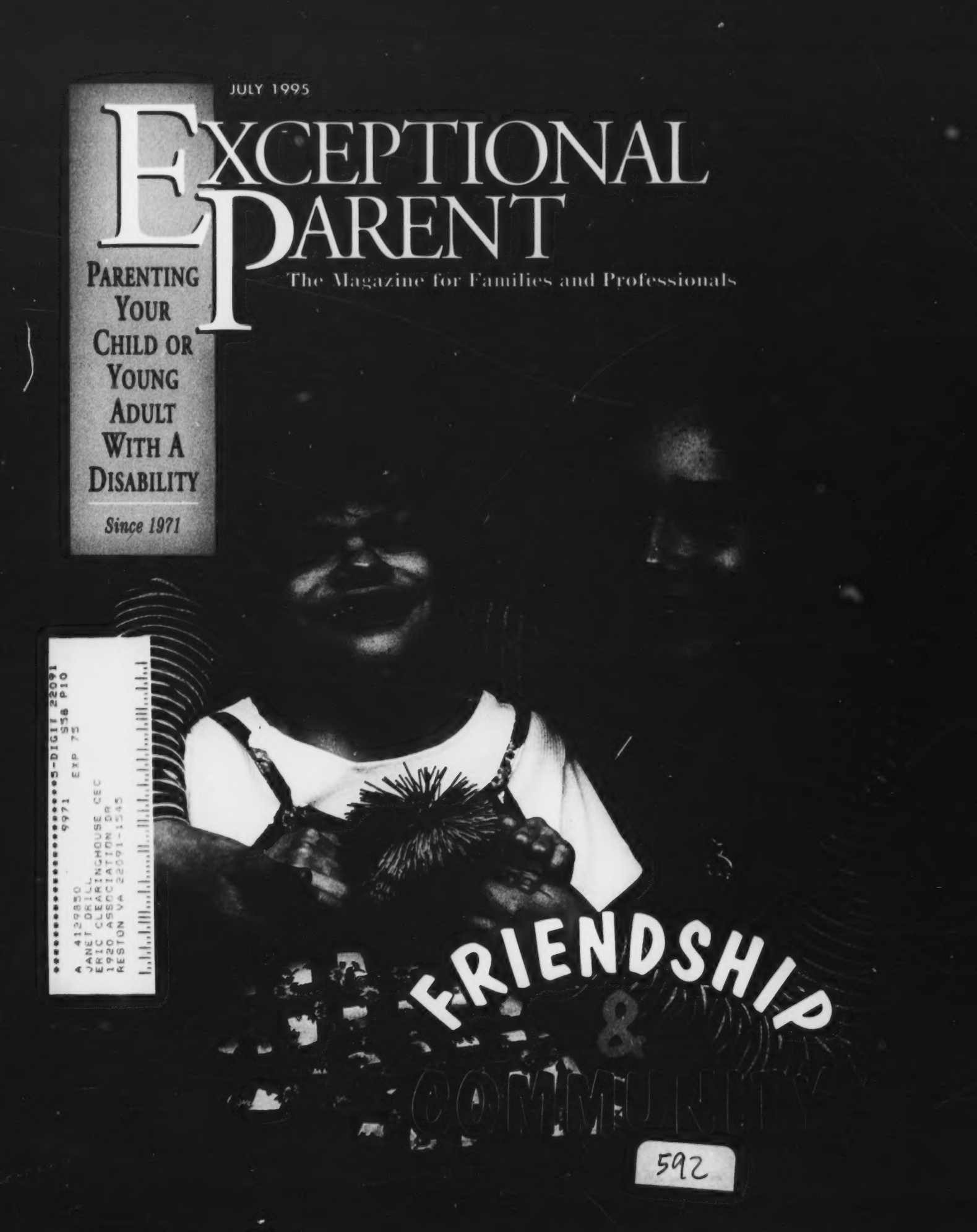

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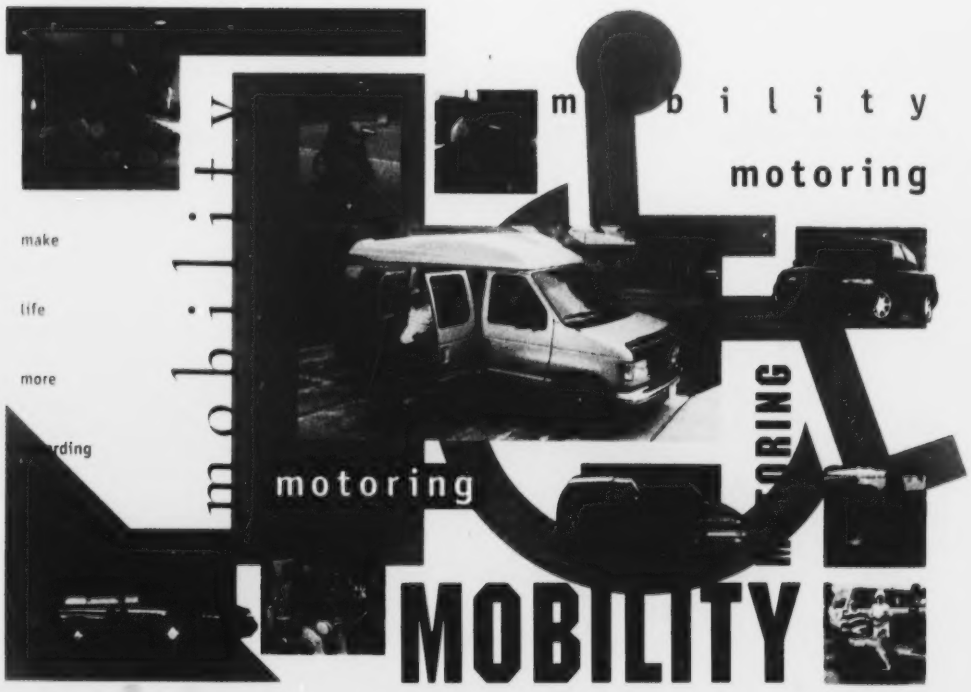

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The Magazine for Families and Professionals

JULY 1995 VOL. 25, ISSUE 7

PAGE 24

Cover: Deanna Simon (left), 20, a student at The Connecticut Institute for the Blind/Oak Hill School, spends some time with her friend Justina Kleczkowski, 12, a student at Slade Middle School, where Deanna's classroom is located.

At Oak Hill, community integration is part of everyday life. It begins at home, where students live in small residences located in family neighborhoods. Opportunities for friendship and peer interaction continue at school, because Oak Hill's educational programs are typically located in public school settings and provide numerous opportunities for shared activities. Photo: Roger Maynard, Applied Photography, Glastonbury, Connecticut.

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EDITOR'S DESK

Community inclusion begins with friendship

As they venture out into neighborhoods and communities—participating in new activities, trying to make friends—children and young adults with disabilities, and their parents, learn a lot about taking risks. There are risks when we try to be independent; there are also risks when we reach out to ask members of the community for assistance.

STANLEY D. KLEIN, PH.D.

As children develop, it is natural that they want to test their abilities and limitations by taking on new challenges. Parents—often recalling their own childhood struggles with similar issues—want to encourage their children, but at the same time, find themselves constantly weighing the potential benefits of a child's participation in any new activity against the risks of pain, injury or embarrassment. Parents seek the perfect balance between protection and overprotection.

In recent years, increased attention has been paid to the development of social skills. Adults have come to appreciate the importance of friendships. Academic or mobility skills are important, but loving relationships contribute even more to a fulfilling life. And participating in a community, with its interconnected network of relationships, is another important part of living.

In this issue, we are pleased to provide wonderful examples of the ways parents and professionals are creating opportunities for children and young adults with disabilities to make friendships and become full participants in their communities. The social commentators who bemoan the disappearance of community life would do well to read the stories in this issue. From Maglia, California, to Rock Valley, Iowa, to Pottstown, Pennsylvania and beyond, these stories demonstrate that communities can respond to the needs of their members in ways that are supportive and meaningful for all. They also show that the inclusion of young people with disabilities and their families enhances the life of the community as a whole—after all, what is "community" if not a place where each person benefits from and depends on the participation and contributions of every other?

The risks of controversy

When we published material on facilitated communication (FC) in our May issue, we knew we risked upsetting some dedicated readers, both parents and professionals. At the same time, we felt we had a responsibility to present thoughtful perspectives on this topic.

It is clear that there are different points of view—as evidenced by both the strong letters we received in response to the May issue and Dr. Biklen's article in this issue. We are committed to providing a forum for caring parents and professionals. That is why Dr. Biklen's article appears in this issue—despite the advice of some people who recommended that we not publish it.

For more than 40 years, I have worked with people with disabilities, their families and professionals. In that time, I have had the honor of meeting many wonderful human beings. Virtually all were caring, compassionate people, deeply dedicated to children and families. However, we have not always agreed with each other on all matters. And there are times when, in the heat of discussion, it can be difficult to disagree without becoming disagreeable.

I am saddened that some readers perceive our reporting on FC as pitting parents against professionals. *Exceptional Parent* has always been dedicated to respecting and supporting the expertise of parents, and promoting the need for parents and professionals to collaborate respectfully. We will continue to publish information and opinions on FC and other controversial subjects, and we invite your participation.

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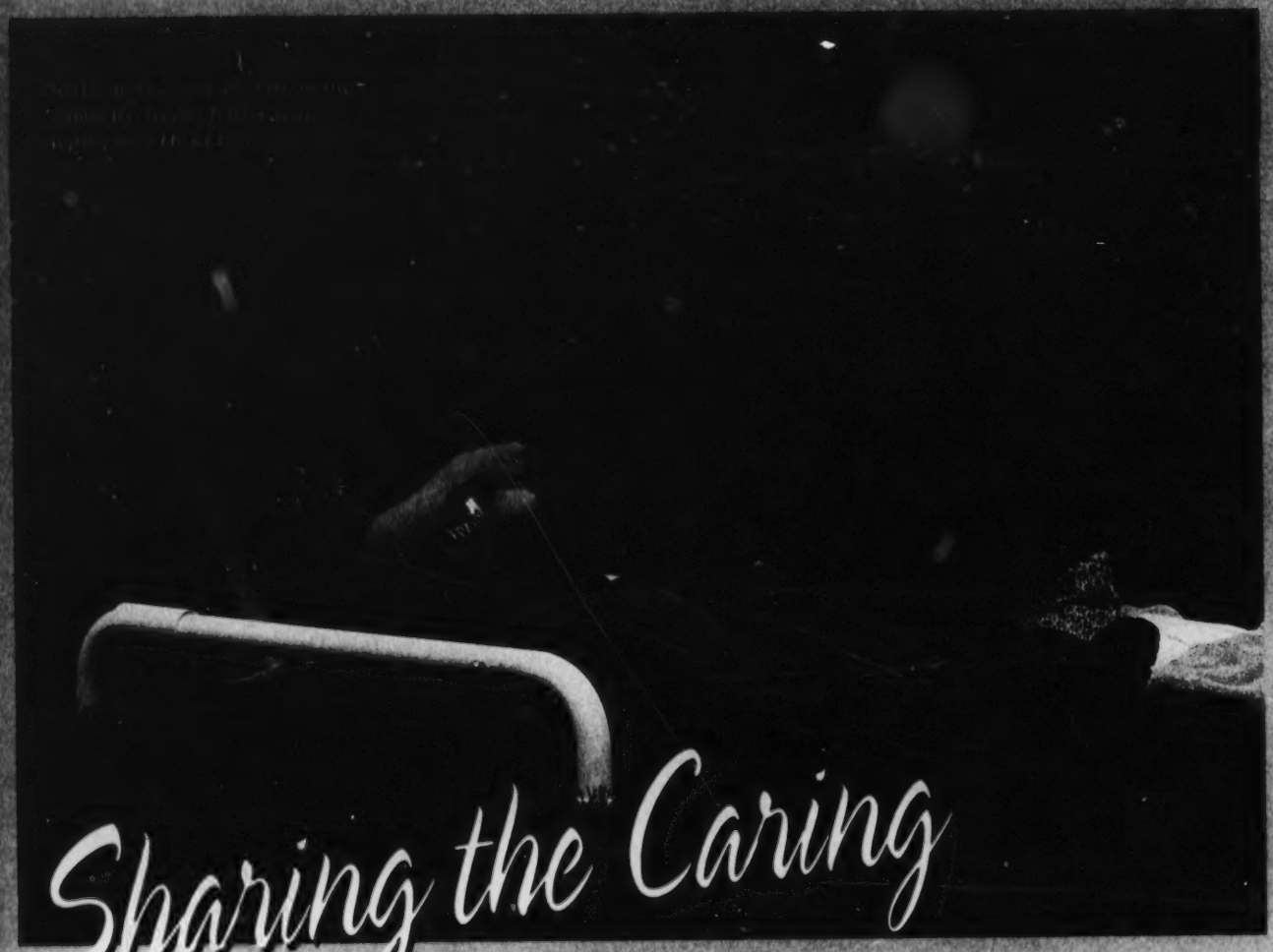

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LETTERS

Sharing Our Children With the World

The April 1995 issue of *Exceptional Parent* included an incredible series of articles describing family vacations enjoyed by families who have children with disabilities. These stories were uplifting and inspiring. I'm sure they will inspire many—including my wife and I—to consider trips hitherto deemed impossible.

After reading all these vacation stories, I came to the last one, entitled "Sharing The World With Our Children." Given the mood and message of all these first-hand accounts, I'd almost suggest changing that last title to "Sharing Our Children With The World." That title would better express another theme and accomplishment of all these stories—the effect on all the people who meet these families on their trips must be very positive and enlightening. Thanks for a great issue!

B.R., New York

Full Circle

I remember the first time I ever saw a copy of *Exceptional Parent*. I was just getting used to the idea of having a baby with Down syndrome, but very worried about what life was going to be like—for him and for me. And there, in the library, on the cover of your magazine was the picture of a smiling child with Down syndrome. At first, I couldn't really look at the child on the cover, I just took quick glances. Every week, I went to the library to find books about mental retardation and child development. Each time, I looked just a little longer at the cover of the magazine. Finally, I took a big step—I opened it!

It took several more months before I actually brought a copy of *Exceptional Parent* home and read it. Now, five years later, there is my son smiling at other new parents from page 26 of the May issue. (I'm startin, to cry as I type this.)

Anyway, what I'm trying to say is *thank you, thank you, thank you* for your work and dedication to serving parents!

Barbara Mitchell
West Liberty, Ohio

EDITOR'S NOTE: Barbara Mitchell's story about her son, "Making Turn-taking Fun," appeared within James McDonald's article, "Turn-taking: A Giant Step To Communicating" (May 1995).

Facilitated Communication

As the parent of an exceptional young man who uses facilitated communication (FC), I was dismayed and disappointed at your supposedly informational article on the topic ("Facilitated Communication: What Parents Should Know," May 1995). Your obvious bias was so blatant I had difficulty finishing the article.

Just because you and other "professionals" don't understand and can't accept a non-traditional method of communication doesn't give you the

continued on page 6

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LETTERS

continued from page 4

right to condemn the process. The "reading and research" you claim to have done focused only on the negative aspects of FC presented by people with another agenda.

I don't claim FC is a miracle or a cure. But it is a means by which nonverbal individuals can express their *thoughts*—not just canned phrases from a language board. One of the first things my son "expressed" after beginning FC was to throw his language board.

That article only focused on the negative situations that can occur when people abuse an FC user. Abuse allegations are the exception rather than the rule, but they get much more attention than all the FC successes. What about the documented use of FC by people who now type independently? Why did you ignore the research done by people like Doug Biklen?

Your magazine has done a grave injustice to FC and to those people who, like our son, can now express their thoughts and feelings. As an apology to their parents, you must publish the research results that show the positive aspects of FC.

Ann O. Reeves
Watsontown, Pennsylvania

■ For "exceptional" parents, there is nothing more burdensome than false hope, and few things more valuable than reasonable expectations. Expectations establish the standard upon which successes and failures are measured. Successes validate our choices and our parenting skills, allowing us to experience pride and happiness in the accomplishments of our child with disabilities. In turn, we are empowered to meet our own needs, and the needs of our spouses and children.

The May 1995 issue of *Exceptional Parent* was most exceptional. Both editor and publisher should be commended for their courage and professionalism. Truth and honesty are the greatest gifts a parent can be given.

G. Emerson Dickman, III
Maywood, New Jersey

■ With the publication of the article on facilitated communication, you have ceased to be a source of valuable, unbiased information for parents. Instead, you have joined the ranks of doctors who believe that people with developmental disabilities can't possibly have any intellectual ability, pedagogical teachers who refuse to relinquish control, and the stifling system of so-called "consumer-oriented" service providers.

After 27 years of silence, my daughter, Leslie, using an augmentative communication device with the therapeutic technique of FC, can tell me when she has a toothache and where and how she wants to celebrate her birthday. She tells us that she taught herself to read by age six and explains about the distortions in her visual

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perception. She can also tell her three-year-old niece, Sarah, that she loves her—with Sarah doing the facilitating. Sarah is a bright little girl but she doesn't know how to spell. Sarah's ability to facilitate with Leslie is one of many confirmations I have had that it is Leslie doing all the talking.

These are Leslie's words—"We are smart. We are waiting so long. We are getting tired. The system prevents the person from getting the proper equipment. The system is the reason we are not productive. The system is doing nothing to help."

Inform yourself, *Exceptional Parent*, and look to the positive research that is available.

Barbara Lockerman
Washington, Pennsylvania

■ Authors Karen Levine and Robert Wharton encourage parents to have FC eliminated from a child's school program when they suspect a facilitator may be influencing communication. But rather than presenting FC as something that either works or doesn't, it needs to be understood as a process that requires ongoing problem-solving and the establishment of safeguards.

Even if parents discover that communication has been influenced, there are potential solutions to that problem that should be tried before they completely eliminate what may be the most valuable augmentative communication system for their child. In addition, parents should be encouraged to have FC included in their child's IEP when it is the child's primary means of communication.

Betsy Knafo
Brooklyn, New York

■ Thank you for your factual, objective article on FC. As a registered nurse and case manager working in the developmental disabilities field, I will not ignore research. It seems that most professionals feel as I do, and FC is now used primarily for personal communication between parent and child. This is probably okay. Mothers and fathers have always "verbalized" their infants' cries—correctly interpreting "you want to be changed" or "you are hungry."

Still, putting exact words in the mouths of others is a scary concept. I challenge all FC believers: do your own investigation—let a machine or other device steady your child's hand. What are the results? The fact that FC often "works" with only one facilitator should be a red flag.

Just last week, I attended a conference where a well-known speaker expounded on the virtues of FC. When the audience asked difficult questions, the answer was always the same—"Just ask the FC user what he or she wants."

Parents who use FC with their children need to ask themselves this question: "When I am no longer around to 'speak' for my child, who will?" Will their daughter someday "request" a hysterectomy because she has stated through FC, "My periods are too painful?" Tough situations like this happen all the time with nonverbal adults, many of whom are cared for by someone other than their parents. As an advocate, I always ask, "Who really wants this, and why?"

Parents and professionals must work together to protect all people who cannot speak for themselves. FC has already caused devastation across the nation. Blindly perpetuating a false theory, no matter how wonderful it seems now, may come back to haunt—no, to harm—the sons and daughters we so dearly love.

Gail Wolf, RN/CM
Roseburg, Oregon

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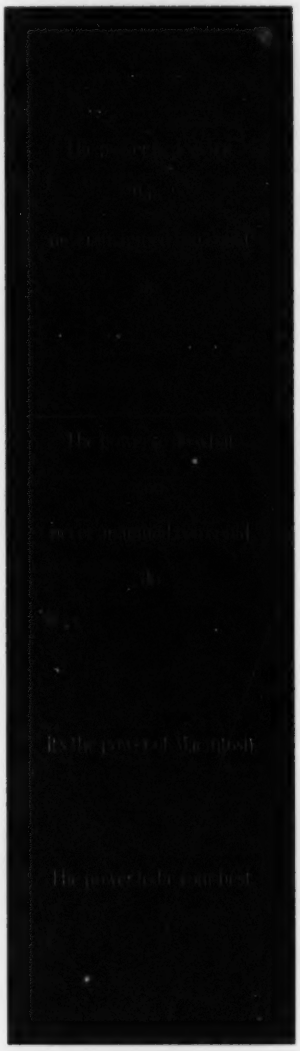
***Write to:** Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*



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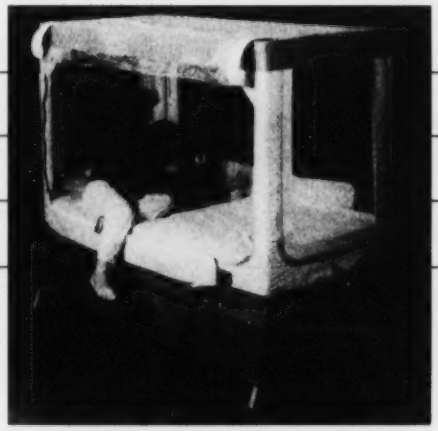

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SEARCH

Self-Stimulation and Smearing

My 10-year-old daughter suffered brain damage at one day of age as a result of hypoglycemia. Aimee has severe mental retardation. She is nonverbal, wears diapers and has an uncontrollable seizure disorder.

At age three, Aimee started touching and rubbing her genital area. I brought this to the attention of her occupational therapist, pediatrician and neurologist. They all said "masturbation" was age-appropriate and recommended that I ignore it.

Ignore it I did. For several years it was not a problem, then Aimee found out how to get her hands in her pants. Eventually, she began to stimulate herself enough to cause a bowel movement. She would then smear herself from head to toe. Her teacher called this "body painting." For a while, I solved this problem by dressing her in one-piece outfits, even making her clothes myself as she grew and it became difficult to find one-piece outfits in her size.

Now, however, Aimee has figured out how to slip her hand up her pants leg to get to her diaper. She has even figured out how to dig her fingers in at the crotch on the outside of her pants. Needless to say, I've had to wash many clothes, and give many baths.

Aimee does not realize that this behavior is inappropriate. I have no way to let her know this behavior is unacceptable. I now hesitate to get babysitters because if Aimee does a whopper of a "body painting" job, they won't come back.

Aimee will soon start summer camp, and I'm afraid there are going to be a lot of problems, especially when the kids go swimming. Aimee has not started menstruating yet and I can't imagine what might happen when she has her period.

Does anyone have any ideas for breaking Aimee of the habit of masturbating and "body painting," or ideas for keeping her hands out of her pants? Aimee's previous occupational therapist, Debbie, has remained a good friend. Debbie is willing to help me create something that would give us a better quality of life. I'm at the end of my rope now and desperately need help.

K.D., Pennsylvania

Residential Care

My three-year-old son has been diagnosed with infantile spasms, microcephally, mental retardation and autism. He lived at home with me until a few months ago. My son's disorders caused extreme behavioral problems; he would scream for ten hours a day. I was constantly exhausted and felt I could not care for him any longer. Finally, I placed him in a residential care facility. I am so heartbroken and depressed. I need to talk to other parents who have placed their child.

K.S., Ohio

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read it monthly.

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continued from page 8

Water Bed?

My one-year-old daughter has spastic quadriplegic cerebral palsy. Because of her limited movement, I am concerned for her comfort and often go into her room during the night to turn her. Although she sleeps on a high-quality mattress with a lamb's wool cover, there is always a dent in the mattress in the spot she has been sleeping.

I am wondering if a water bed or any other type of special mattress might be more appropriate and comfortable for her. I would appreciate advice from parents who have had experience with different types of mattresses.

D.S., Massachusetts

Chromosome 18p–

My 16-year-old daughter was born with a partial deletion of the short arm of chromosome 18 (18p–). As an infant, she had hypotonia (low muscle tone) and developmental delays. At the age of 12, she developed muscle spasms and tremors. Doctors tell me that they know of no other person with 18p– who has developed these symptoms. I would like to hear from anyone whose child has similar problems.

C.W., British Columbia, Canada

EDITOR'S NOTE: The Chromosome 18 Registry and Research Society (6302 Fox Head, San Antonio, TX 78247; 210/657-4968) can put you in touch with other parents of children with 18p–. Their registry currently lists 51 children with this condition.

Peters Anomaly and Dental Problems

We are the parents of a happy, two-year-old named Benjamin, who has Peters anomaly (a condition where there is adhesion of the cornea to the iris). As a result, he has congenital glaucoma and vision of approximately 20/600. In addition, he has hypotonia (low muscle tone) and developmental delays.

Despite his disabilities, Benjamin gets around very well. He crawls everywhere and is starting to stand without support.

Now, we have a new concern. Benjamin has only nine teeth, and half of them have come in fused. We have taken him to a pediatric dentist, who has answered some of our questions, but we would also like to correspond with parents who have a child with this type of dental condition, or any parents of children with Peters anomaly.

R.L. & C.L., Michigan

continued on page 12

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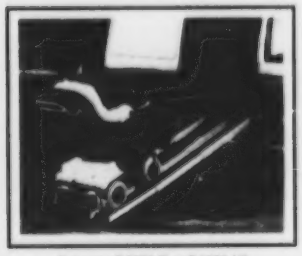

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The joy of anticipation was all over his face...Troy's dad was taking the training wheels off his bike. His dad helped him get started...then, he let go...and Troy was doing it, he was riding all by himself!

Troy's father knew that sometimes the hand that helps most is the hand that lets go. So did the parents of Victor, a young boy with multiple disabilities.

Victor was 13 years old when he arrived at Heartspring's residential school. He was unable to tolerate being around a lot of people. Crowded rooms or noisy hallways frightened him. He couldn't seem to participate in the real world.

From the very beginning, Heartspring staff worked with Victor's parents, school districts, and other professionals, setting goals so he could gain the independence he needed and return to his home community.

Now, five years later, Victor attends public high school classes for a couple hours, then goes to work at a restaurant on the campus of a local state university. He has learned to tolerate walking in hallways that have over 1,000 students on their way to class! Currently, staff are working on other needs Victor has to ease his transition from Heartspring to his home community.

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Circle #3

SEARCH

continued from page 11

Developmental Apraxia of Speech

My five-year-old son was diagnosed with developmental apraxia of speech (DAS) several years ago. I have been unsuccessful in my search for information on this subject. Are any universities or clinics doing research on this condition? I would like to hear from any therapists or educators who have worked with children who have apraxia.

Finally, I would appreciate hearing from parents of children with DAS. Is there a DAS support group out there somewhere? I want to sign up!

S.A., Arkansas

EDITOR'S NOTE: The National Organization for Apraxia and Dyspraxia (7675 Charter Oak Dr., Pennsecola, FL 32154; 904/478-4895, voice; 904/494-1444, TTY) can provide information about DAS. They can also put you in touch with other families dealing with this condition.

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
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Exceptional Parent
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Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

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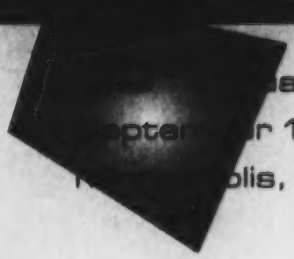

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RESPOND

Dealing with Seizures

D.R., (May 1995) has a son, Christopher, who is almost three years old. He has cerebral dygenesis, meaning that roughly half his brain is gone. He has developmental delays, hypotonia, slightly clubbed feet, farsightedness and a seizure disorder that is mostly controlled by Dilantin. But when Christopher does have a seizure, he stops breathing. D.R. wanted to know how other parents deal with seizures, especially how they sleep at night.

My family and I could write a book about seizures. Our son, Timmy, is four years old now. When he was 23 months old, we were told he had severe mental retardation. Boy, did those words change our world! But, later that month, we found out what it was really like to have the walls come tumbling down; that was the day Timmy had his first of many seizures.

We found Timmy in a pool of vomit in his crib. At first, we thought he had just spit up and gone back to sleep until my mother-in-law, who is a nurse, scooped him up and started doing CPR. Then I realized my son was not breathing, obviously had not *been* breathing, and could very well die.

Since we lived in a small rural town, the local hospital promptly flew Timmy to a major medical center. We had to drive for 45 long minutes, not knowing if he would be alive when we arrived. He was started on Dilantin and was fine for just two days when he had another seizure—and this one lasted for three hours!

Since then, Timmy has had more seizures than I can count. With every one, he has stopped breathing—just like your son.

Last November he had the scariest seizure of all, because we didn't know it had happened. Again, we found him in a pool of vomit. His lips, fingers and toes were blue, and he was scarcely breathing. To top it all off, our wonderful pediatrician was out of town. All doctors deserve a vacation, but he chose to have his when Timmy was crashing! Thank goodness we were able to reach Timmy's neurologist who promptly met us at the emergency room. By that point, Timmy's vascular system had shut down; they had to stick him 27 times to start an IV. While Timmy was in the hospital, his neurologist told us about a new seizure medication, Neurontin, that he thought would help Timmy. Timmy started on Neurontin the day that he was discharged from the hospital and has not had one seizure since—*not one.*

We do know what your life is like! After Timmy's seizure in November, we felt very guilty that we hadn't

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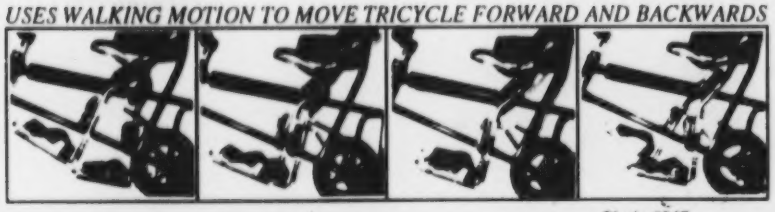

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Circle #247

checked on him sooner and caught the seizure earlier. We know what it's like to go without sleep. We are up a lot at night just to check on Timmy; we can't sleep at all if we don't know he is OK.

I would suggest that you try to find a back-up system for yourselves. It has taken us a long time to be able to trust anyone but ourselves with Timmy, but we can't let ourselves go crazy worrying; sometimes, we just need a break.

Check into your local resources, and see if you can obtain a list of respite care providers. If respite care is not available, you might try placing an ad in the newspaper for an occasional caregiver who is trained and certified in CPR. Or, you might try calling the special education department of a nearby college. That's how we found our babysitter, a terrific young woman who is a speech/language pathology major at the local university. She babysits for us on weekends and occasionally during the week.

I'm not going to lie to you—you probably won't ever sleep a full night again as long as Christopher has seizures. But, with help, you just might be able to keep your sanity.

You are not alone! It is nice for me, too, to be in touch with other parents who are going through the same things. My mother always says God doesn't give us any more than we can handle. Sometimes, I believe her; sometimes, I don't.

E.F., Georgia

Stressful Car Rides

C.R. (May 1995) has a 26-month-old son, Austin, who does not have a specific diagnosis, but has been labeled "centrally hypotonic" (having low muscle tone). Austin becomes very upset while riding in a car seat. His parents have tried different car seats and different seats within the car, however, Austin continues to become upset when they put him in the car—crying, screaming and holding his breath until he passes out. C.R. was looking for ideas for making car rides less upsetting for Austin and less stressful for his siblings.

Our wonderful 16-month-old daughter, Sophie, has a peripheral sensory neuropathy and has been centrally hypotonic from birth. Sophie hasn't gotten upset in her car seat lately, but in the past, I found that sunlight and rapid light changes (like those experienced while riding down a tree-lined street on a sunny day) seemed to irritate her. Street lights at night also bother her. We try to keep sunglasses on her and shades around her seat; throwing a light-weight blanket over her car seat actually works best. Though doctors say Sophie's eyes are normal, we feel her system is slow to process and react to changes in light. She also seems to dislike certain noises, like crowds clapping and the noise the car makes on windy days.

We'd love to correspond with you and "compare notes."

J.P., Illinois

608

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Circle #98

Tom Hershey

"My family was a team."

Tom Hershey, 32, is director of operations/associate producer at Sony Pictures Imageworks in Culver City, California. He was born with a still-undiagnosed disability that affects his stature and mobility, and that triggered a kidney disorder at birth.

The following was adapted from a recent interview between Hershey and EXCEPTIONAL PARENT *editorial intern Jennifer Koerber.*

Tom, 12 months, enjoys a tender moment with Mom. At this point, Tom's parents weren't really thinking about his other disabilities. His life-threatening kidney disorder overshadowed all other concerns.

My family has always been a team that has worked together to make me self-sufficient. I think their reaction to my disability was a decision not to concentrate on the disability, but on the child. This attitude defined the way they dealt with it, and with me, over the course of my life.

A homegrown approach

Shortly after birth, I developed a life-threatening kidney infection that required four operations before I was four years old and led to the loss of one kidney. During those years, my health was very touch-and-go. As a result, my disability as a whole was considered a lower priority than its most life-threatening symptom. After my kidney was removed, I started eating better and gaining weight. My parents were then able to begin to think about my other problems. In a way, the immediate danger of the kidney disorder made the disability itself much more manageable.

After two years in Hawaii, Tom's family returned to the mainland when he was seven.

At the time I was born, there was a great deal of interest in genetics and chromosomal disorders. I was first evaluated at the Naval Hospital at Bethesda, Maryland. The doctors looked at my malformed left arm and leg and said, "Yes, this is a very interesting chromosomal disorder. We'd like to run some tests." They tested my chromosomes and said they'd found several anomalies.

When I was five, my father was transferred to Hawaii. A team of doctors at the army hospital decided to do their own chromosomal studies. Their tests came back normal. The doctors back east had either made a mistake or were only seeing what they wanted to see. My parents began to lose confidence in the medical profession.

My parents did stick with the "experts" a bit longer. Unfortunately, the physical therapy program at the military hospital wasn't geared toward children, or other people like me. It was the first stop for Vietnam veterans with disabilities before they returned to the mainland; so the PT regimen focused on strengthening other parts of the body to replace missing or damaged parts, rather than trying to improve the muscular system as a whole.

The hospital was an enormous facility. My mom had to push me in my wheelchair down miles of corridors. Her solution? She brought my tricycle from home and let me ride it from the parking lot to the therapy room. Slowly she realized that by using the tricycle and another little car that I pumped with my arms, I was building up more muscular strength than I was in my therapy sessions.

My mom resolved to find alternate ways to help me build up my strength. This time, the solution was a little closer to home—the military officers' club swimming pool. We had befriended the pool's lifeguard, Ed Rother, a retired Army football coach. My mother approached Ed, and asked him if he would consider developing a swimming program for me. He agreed.

This occurred during one of my father's tours in Vietnam. At the time he left, I didn't have the muscle strength to lift my head out of the water. Ed began by rigging up a snorkel for me so I could breathe. I swam every day, and rode my tricycle and the little car around the neighborhood, too. By the time my father got home, I was swimming a quarter of a mile a day and diving into more than 10 feet of water to find a golf ball. All this in about six months! My father was amazed at the change this homegrown therapy had made in me.

Part of the fabric

The next watershed in my life came after we moved from Hawaii to Vero Beach, Florida. At that time, I had two

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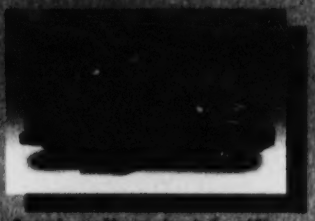

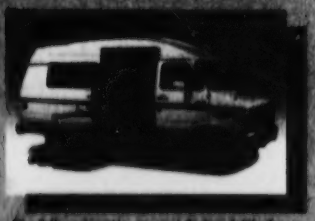

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At age 10, Tom was an enthusiastic Boy Scout.

Role Models

continued from page 16

operations to lengthen the muscles in my legs and stabilize my feet. I did some basic recovery therapies after these operations, but I also kept swimming. By this point, I had enough strength to use canes and a walker at home; I only used my wheelchair at school.

A more important change came through my enrollment at St. Edward's School, a private school in Vero Beach. Headmaster Peter Benedict was willing and eager to help a kid who had some physical disabilities and mobility problems, but who had tested very highly in placement exams.

My parents felt able to shift their focus from my physical needs to my academic and social skills. My mother loves to tell the story of a day when she came to pick me up from school. She saw somebody pushing a wheelchair with a child in it through the trees near the playground. With all the kids running around and having a great time, it took a moment for her to realize that it wasn't me in the chair. I was hiding behind a log, fighting my part of a mock battle from behind the lines. It was at this point that she realized I was going to be integrated into the fabric of these children's lives.

Academically, my adjustment was a little more complex. My first teacher at St. Edward's was an old-school type who immediately laid down the law with my mother—"He may have gotten special treatment elsewhere, but not in this class!" My mother got ready for a fight, but that teacher had my best interests in mind. The teacher knew instinctively that she had to let me flounder for a little bit so I would learn how to pull myself up.

A pragmatic attitude

My parents always wanted to make sure that my physical, intellectual and social development were happening together; they hoped to avoid a focus on one at the cost of the others. This pragmatic attitude ruled all aspects of their lives. My parents didn't dwell on my disability, nor the effect it had on our lives. My dad had his job to do with the Navy; my mom had her job to do with me. They were both motivated by the fact that they believed in what they were doing.

If my parents had so-called "typical" feelings like guilt or

continued on page 20

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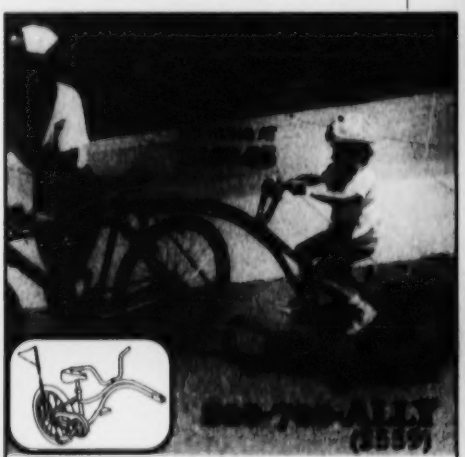

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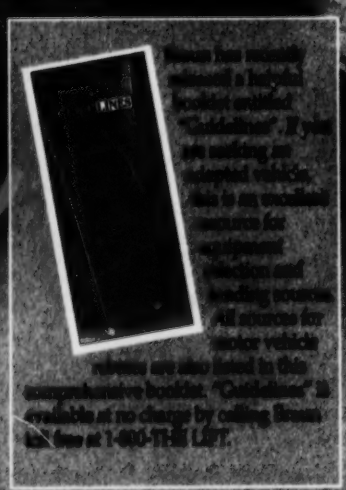

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continued from page 18

anger, they were kept from me. Like many military families, we—my parents, my sister and I—were a team. Moving from base to base in my early years taught us independence from standard social services; we relied on other members of the family for support. For better or worse, military life isolated our family from many outside influences.

Tom enjoyed a 1994 vacation in the mountains—even though he neglected to pack sufficiently warm clothing!

Necessity and invention

I have always loved movies, so it was no surprise that they have become my career. At the Massachusetts Institute of Technology (MIT), I majored in management with a minor in creative writing. My work in the MIT media lab and courses in entertainment marketing fed my love of film and led me to the MBA program at UCLA, where I concentrated in entertainment management. From there, it was a short hop to Hollywood, and here I've stayed.

While attending both MIT and UCLA, I was a volunteer peer counselor for students with disabilities. I got involved because I had to sit down with the person in charge of disability services and create a plan for getting around the campus. In the disability services office, I often saw college and high school students who were touring the university and trying to find out more about disability services. Most seemed very unsure about leaving the security of home. So I offered to speak with any students who wanted to talk to somebody who was out in the world and surviving. That one little offer of help allowed me to talk to a lot of students who came through the university.

Upward swing

My life has been on an upward swing since birth. Most of the time, I don't really think about my disability. The only time I'm faced with it is in a new situation; then I take 15 minutes, figure out how I'm going to do something and then go from there. My disability has always been a part of my life, and it gets more attention from other people than it does from me.

My parents taught me not to be afraid of the unknown and to be inventive about creating ways to be self-sufficient. I'm a little wary of over-reliance on systems that are in place, because I think that may dull the edge of the inventiveness and creativity that you can bring out in children with disabilities. Being able to figure out when any given form of assistance works and when it's not the best alternative may be the most important skill they ever learn. **EP**

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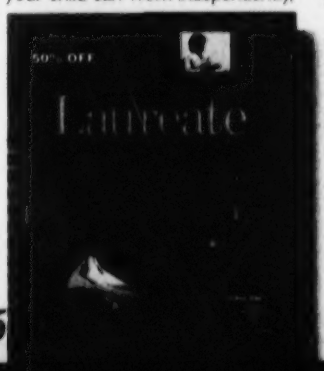

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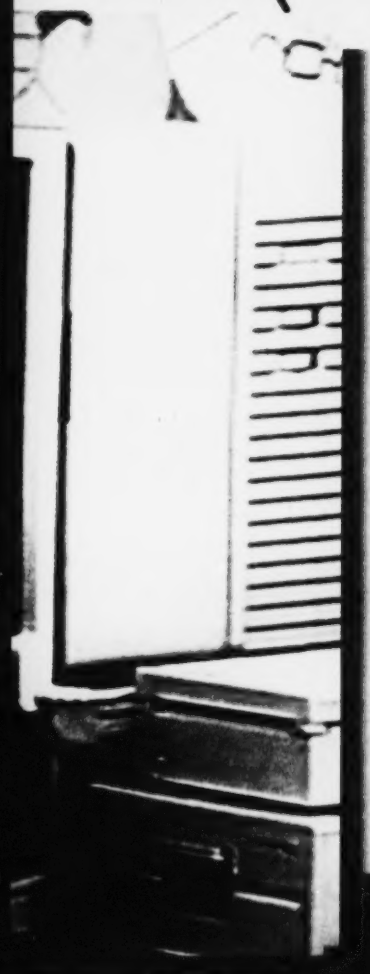

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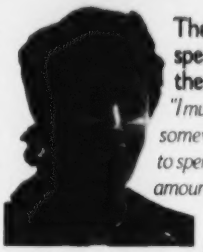

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Circle 948

On "opening day" of the Friendship Club, children proudly wear their newly-created membership badges. Surrounding Erin are (from left) Kaylin and Ryan Gain, Harmony Baker and Kristen Gain.

FRIENDSHIP

Erin's Friendship Club

by Donna Tatro

I'm embarrassed to admit it, but from her earliest days I've used bribery in trying to establish friendships for my daughter, Erin. I can still picture my first attempts—as neighborhood kids played on the lawn in front of our triplex, I'd spread out a large blanket and some of Erin's most stimulating toys. Then, with two-year-old Erin in my lap, I'd spill a large bag of M&M's out in front of us. As I caught the kids glancing in our direction, I'd call out, "Hi, what's your name? This is Erin. Would you like some M&M's? Ask your mom if it's OK."

With a handful of kids sitting on our blanket, I seized the opportunity to teach them about cerebral palsy and blindness. They came to understand that nonverbal doesn't mean dumb; the girls even asked me to help them make gastrostomy tubes for their dolls because, "just like Erin," they couldn't "swallow good."

Soon the neighborhood children were asking if they could come inside to play. Erin's therapy equipment—large balls, colorful wedges and tumbling mats—looked like a lot more fun than the toys at their homes. I always kept snacks in the cupboards, too, even though Erin couldn't eat them. And—I admit it—I tried to create some envy when I bought a hamster for Erin's third birthday. "Rodie" worked; she drew the kids over for frequent visits.

Nick Brown (right) and Erin enjoyed feeding the animals during a trip to a petting zoo.

Wanting Erin to enjoy life from a kid's perspective, I often asked my neighbors if I could take their kids on a walk, to the library, to the park or to the zoo. Outings were more exciting for Erin when she could hear and feel the excitement of other children.

Later, we found ourselves across the continent living in an apartment complex full of senior citizens and no other children. I spent time at Erin's preschool and got to know the other children and their parents. Again, I went out of my way to invite her classmates to afternoon or weekend outings with Erin and myself. I would always scan the newspaper to keep abreast of special events for children. And even though Erin is fed solely through a g-tube, every outing included a stop at an ice cream shop or McDonald's to treat her friends. As you might imagine, Erin soon became very popular.

"Bubbly Day" was gleefully celebrated by (from left) Danyel Stoltey, Harmony Baker, Erin, Jenny Nunez, Amanda Jones and Lyndsay Nunez.

Filling the summer calendar

The school year had been filled with friends and activities. But as Erin's kindergarten year came to a close, I feared a lonely summer. Though she attended the local school, ours was a mountainous community where most children rode the bus. There were no children Erin's age living nearby. I knew that most of Erin's friends would not be allowed to call and ask if they could come over; most of their parents saw our life as overwhelming, and they didn't want their children to impose. "How do I make people understand that I *want* them

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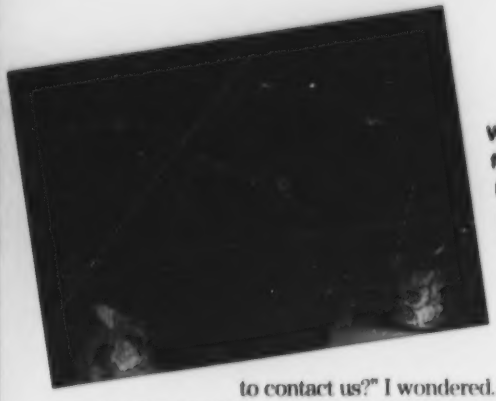

With a little help from my friends: Harmony Baker (left) and Brandy Surplus help Erin with an art activity.

to contact us?" I wondered. That's when I got the idea for "Erin's Friendship Club."

I began by filling up calendar squares with enough activities to occupy every summer week. Ryan, the fifth grade boy who had been Erin's "big buddy" in kindergarten and her helper in Challenger Little League, accepted my offer to be the club president.

I sent the calendar to dozens of Erin's friends from her kindergarten and Sunday school classes and her Daisy Girl Scout troop. In my accompanying letter to their parents, I discussed Erin's disabilities and explained what their kids would encounter at our house—positioning equipment, therapeutic "toys" and various types of medical equipment. I told families that we had invited other children with disabilities to join the "club," and stressed that it was our philosophy that diversity and uniqueness need to be celebrated.

With only a few exceptions, nearly every day was booked. Activities included "camping day" (we opened up the camper and called the wading pool our lake), "bubbly day" (we got out bubble wands and filled the wading pools with bubble bath), "hairy day" (we made our own barrettes and pony tail bands) and "square eyes day" (we watched favorite videos and made popcorn). We also made trips to the skating rink, the park for picnics, a local pond to feed ducks, the bowling alley, a big city shopping mall, the zoo, a matinee movie, a nature center, Erin's great-grandparents' home and Marine World. Other activities included cooking, computer games, dancing and art activities. I even invited a friend to join Erin's weekly trips to physical therapy.

It worked out wonderfully. Friends would look at Erin's calendar and decide if she was doing something they'd enjoy. Then they'd call and make reservations to attend. Some days, Erin had only one friend come over; other days, we hosted as many as 10. I canceled only one activity due to illness. At other times, if Erin wasn't feeling well, she'd just sit back while her friends played. Best of all, both Erin and I established deeper relationships with kids and their parents.

Back to school

When first grade started, many of Erin's kindergarten friends were in her new class. To help the children who didn't already know Erin, I attached a small photo album to Erin's chair. In it are pictures of Erin doing typical kid things—swimming in the pool, riding an adapted trike, holding her doll, cooking with mom, and doing things with friends. The photo album is very popular with the kids; nearly every time I'm at Erin's school, I see at least one child thumbing through it. It's a great way to let others know that despite Erin's obvious disabilities, she's still just a kid. **EP**

Donna Tatro lives in Magalia, California with her husband, Gordon, and daughter Erin, 7. Donna is actively involved in helping other families obtain needed services and full inclusion in their communities and schools. In her free time, she enjoys gardening, sewing and reading.

Dear Parents,

The first week after school let out was enough to let me know that I would need to organize some activities for Erin. She was one bored kid; Mom just doesn't make the best playmate! Phone calls to friends told me we weren't alone. Also I know parents assume that our circumstances are such that their kids would be a burden to have over; I've never found that to be the case. Rather than me getting on the phone daily to find friends to come over or go places with us, this Friendship Club has been organized with already-planned activities.

I have invited other children with disabilities to join our club. I'd like the kids to understand that we all need friends, regardless of our abilities. Diversity and uniqueness need to be celebrated.

We treat Erin's disabilities in a matter-of-fact way. I'm happy to answer questions that the children raise (and I don't discourage them). You'll find that the children will have a matter-of-fact acceptance of Erin's circumstances--often sooner than adults. You should know that in our home they'll be exposed to a lot of different types of positioning equipment, such as walkers and standers, and therapeutic "toys." At Erin's bedside are three machines--a feeding pump, a suction machine and a nebulizer machine for breathing treatments; I've found that kids ignore these for the most part. Erin has "buttons" in her abdomen through which she's fed. I don't hide this from the kids; in fact, I encourage them to help. If your child tells you that he or she gave Erin a shot, don't worry, it's not true. Erin's medications are drawn with needleless syringes, then pushed through a "straw" into her tummy; I let the kids help with this. You're welcome and encouraged to come for a tour, to observe and to ask questions.

The club will be an opportunity to develop and reinforce friendships with others. It may also be an answer to the summertime boredom blues. Even if your child does not join the club, please come to some of the special outings that are listed in the calendar. We hope you'll want to join in!

Donna Tatro

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READERS TALK ABOUT: Friendship

Rescue 9-1-1

A few weeks ago, my 10-year-old daughter, Sophie, invited a friend over to play at our house. Sophie is the only child with a disability in her school. This, however, has not stopped her from making friends in her class.

That Saturday, her good buddy, Shane, came over to play. At one point, Shane chose to stay upstairs and play while Sophie went downstairs to watch a video.

After awhile, Sophie got impatient.

"Shane!" she shouted loudly, "Come down here right now!"

"No!" answered the indignant Shane, still involved in his Lego castle upstairs.

"Shane, if you don't come down here and watch TV with me, I'll call the police!" warned Sophie.

"Oh, Mister Tough Girl," replied Shane, valiantly holding his own.

"I am not a 'mister'," Sophie yelled up the stairs.

From the other room, I listened to this exchange with amusement, proud that my daughter was having a good old verbal knock-down, drag-out argument with another kid. Because Sophie was born with Down syndrome, I am always encouraged when she acts like the standard-issue 10-year-old, even if it means being crabby.

A few minutes later, after the argument seemed to have died down, I was setting hot soup and big crunchy crackers on the table for the kids' lunch. As they started to eat, there was a knock on the door. I opened it to my friendly neighborhood police officer.

"Ma'am," he addressed me formally, "Did someone dial 9-1-1?"

"Uh," I turned red, "I think I can explain, Officer." I told him about the domestic quarrel between Sophie and Shane. Apparently Sophie had made good on her promise and, unbeknownst to anyone, had dialed 9-1-1, probably while I was making the soup.

From their seats at the table, Shane and Sophie could see that a real policeman was at the door. Sophie was looking halfway smug, as if to say, "See, Shane, I told you so…" but also halfway worried.

When I returned to the table, Shane, a look of shock on his face, was repeating, "Sophie, I can't believe you called the police!"

HAVING A FRIEND MEANS WORKING IT ALL OUT TOGETHER, EVEN THE WACKY STUFF. AND THAT'S A LESSON FOR EVERYONE—NOT JUST FOR KIDS, AND NOT JUST FOR KIDS WITH DISABILITIES.

I took Sophie aside and reprimanded her. I told her that she should only dial 9-1-1 in an emergency—like a fire or if someone were hurt. In no uncertain terms, I let her know that she was not to call the police on her friends. She looked downcast and appropriately chastised and told me she understood.

Of course, in a perverse way that probably only another parent of a child with a disability could fully understand, I was thrilled Sophie could dial 9-1-1 and make the police arrive! Truth be told, sometimes I wish I could call the police on my friends—or my husband—when they won't do what I want.

The good news is that a little while later, Shane and Sophie went back to playing happily with each other, their friendship none the worse for wear. I guess that having a friend means working it all out together, even the wacky stuff. And that's a lesson for everyone—not just for kids, and not just for kids with disabilities.

— Jolie Kanat
Belleair, Florida

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of Exceptional Parent. In upcoming months, readers will be talking about:

- children's favorite toys and playtime activities (October; deadline Aug. 1, 1995)
- technology—how has it made a difference for your child? (November; deadline Sept. 1, 1995)
- grandparents/extended family (December; deadline Oct.1,1995)

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

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Just Friends

See ya later, Mom! Liz (right) and Allison are on their way "out."

It's Wednesday night, time to call Allison! It's a regular part of Liz's midweek routine to call her friend and make plans for the weekend—just like any other 16-year-old girl.

For a long time, Liz's dad, her brothers and I wondered whether this typical teenage activity would be something Liz would get the chance to experience. For years, *we* had been her "friends." We tried to do fun things with her—together and separately—that would fill her leisure time and give her something to look forward to. For a long time, this seemed to be enough. But as Liz grew older, it became clear that there was one thing all teenagers need that we could not provide for her—time away from her family. Then I heard about the Just Friends program.

Just Friends—a program of GOARC (Association for People with Mental Retardation and Other Developmental Disabilities in Omaha, Nebraska)—is a one-to-one friendship program that allows teens with disabilities the opportunity to interact with peers without disabilities.

Just Friends matches teens with disabilities to teens without disabilities. Matches are based on interests, ages and home locations. Volunteers without disabilities are asked to commit four hours a month for one year to the friendship. What the two individuals do during this time together is up to them.

In addition to making one-to-one matches, Just Friends also sponsors several group events and activities every month. These events provide interaction activities for teens who are waiting for a one-to-one friendship. The group events also provide community involvement as Just Friends participants attend events for teens that are run by other organizations and members of other organizations are invited to Just Friends events.

Liz was introduced to her current friend, Allison Holt, in April 1994. Liz, 16, attends the Madonna School for Exceptional Children. Allison, 17, is a junior at Millard North High School. Liz and Allison do something almost every week. The activity itself doesn't really matter. What matters is that Liz is able to get in the car, leave her parents at home where they belong and just "hang" with a friend.

Liz has learned a lot from the Just Friends program and from Allison. She has learned how other kids her age feel and act. She has learned about loyalty and commitment. She has learned how to answer the age-old questions: "Where did you go?" ("Out") and "What did you do?" ("Nothing"). But, most importantly, she has learned what it means to have and be a friend.

— Jean Sigler
Omaha, Nebraska

Appreciating Differences

Erin Callahan, 6, and Michael Festino, 4, excavate a sandbox "construction site" at the local park.

As special educators, my husband and I are committed to the inclusion of children and adults with disabilities—in schools, communities and the workplace. Our own daughter, Erin, does not have disabilities, but we wanted to instill in her an appreciation (as opposed to just tolerance) of differences in others. We knew that talking about diversity wasn't enough—Erin needed to have the experience of being around people who others might view as "different." Through exposure, we felt our daughter could develop friendships with a diverse group of people.

My husband and I have culturally diverse friends and friends with disabilities, so Erin has always had lots of exposure to adults who are different from Mom and Dad. But we also wanted Erin to be open to having friends with disabilities who were closer to her age. Those opportunities became available when Erin started kindergarten and a child with autism was included in her classroom. The kindergarten teacher created an atmosphere of acceptance through both word and action. This outstanding teacher treated Christopher as one of the gang, being matter-of-fact about his occasional need for extra attention.

One day, I visited the classroom during "circle time." As the other children sat on carpet squares listening to a story,

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Christopher walked around the classroom. Erin saw me start to approach him and quickly intervened. "Mother, it's OK," she told me. "Christopher *needs* to walk around some." I realized Erin was learning in her own way that children have different needs at different times.

During that same year, our family developed a friendship with another family that included a four-year-old boy with Down syndrome. I didn't feel the need to "set the stage" for the children's first meeting by explaining about Down syndrome. I wanted Erin to get to know Michael first; the questions would come later.

After spending some time with Michael, Erin asked me why he doesn't talk very much. I told her that some children have difficulty using words to talk; instead, they may use sign language, picture books or computers. Erin also asked if *she* could get Down syndrome. I explained that children are born with Down syndrome, that it is not an illness. I try to choose my words carefully so as not to diminish the person with a disability; I also want to be sure that my explanations don't make Erin afraid to interact with another child. In fact, Erin and Michael have become great friends. They enjoy going places with each other and spending time at the other's home.

Here are some suggestions I'd give other parents who are trying to facilitate these kinds of friendships:

- *Answer questions.* Don't make a child feel embarrassed about asking questions. When answering questions, be honest and direct.
- *Avoid labels.* Instead, describe the child with a disability in positive ways. Instead of saying, "Johnny doesn't talk," you can say "Johnny talks with his hands."
- *Make inclusion a regular habit.* Take advantage of everyday opportunities such as birthday parties and weekend outings to include children with differences, so friendships have a chance to grow.

— Teresa R. Callahan
Ocean Springs, Mississippi

Special Friendships

Lately, friendship has been one of my top concerns for both of my children, one of whom has severe physical, intellectual and visual disabilities. In meetings with other parents of children with disabilities, I find they are also preoccupied with the "friend situation." I think many of us have started thinking about friendship because the inclusion movement has made us question *all* the limits placed on our children's lives, whether or not our children are involved in "inclusive" education.

I am troubled, however, that other parents rarely consider other children with disabilities as potential friends for their children. We expect parents of "regular" children not to discriminate against our children, but we discriminate against them ourselves. I'm not saying that the friendships of a child with special needs should be restricted to other children with disabilities, but I strongly believe that the possibility of such friendships should not be dismissed.

My four-year-old son, Isaac, has such severe disabilities that the other children who attend his special education program do not provide friendship opportunities in the usual sense. It is clear, however, that he enjoys their company. His teacher tells me that he constantly approaches his classmates and attempts to initiate social interaction. Sometimes, he and another child will sustain an ongoing interaction for a fairly extended period. It is distressing to me that the parents of these classmates do not seem interested in trying to support these "friendships" outside of school.

I have been fortunate to become friends with the mother of a boy who has disabilities somewhat less severe than Isaac's. This mother has also been interested in promoting friendship between our sons. Isaac and her son, Brian, enjoy each other's company and meet each other's needs in ways that "regular" friends might not. Both boys enjoy a level and type of physical contact that is not typical of boys their age; they also enjoy many of the same play activities. I know the other boy looks forward to his play dates with my son and likes having a true friend. And if Isaac could communicate such an abstract thought, I'm sure he would say the same.

Isaac Sugar, 4, (left) enjoys playing with Brian Matsumoto, 5.

I don't mean to say that my son cannot be friends with a child who does not have disabilities. Isaac certainly enjoys the company of "regular" children. He also benefits from exposure to children who use language well and behave in an age-appropriate manner. In return, Isaac offers these children an enjoyable experience free of competition and aggression. He is unreserved about expressing affection and admiration. These children may also learn that the differences between themselves and my son are not so great as they may first seem.

I certainly hope that Isaac will have good friends in the years ahead. I fully expect that many of those friends will have some sort of disability. Having a friend with disabilities does not make Isaac more "disabled," any more than befriending my son would reveal a failing in a "normal" child. My goal for Isaac is the same as my goal for everyone else in our family—to be open to friendship whenever an opportunity presents itself, and to create such opportunities whenever possible.

—Lynne Tamor
West Bloomfield, Michigan

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Familiar Faces

FRIENDSHIP

When these friends hit the mall, the Disney Store is their first stop. **Angela Hope Litterilla**, 14, is surrounded by (from left) **Brittney Otterback, Kathy Reyna, Hillary Bertran-Harris, Claire Andrews, Trish Howard** and **Nicole Myers.** Friends since the fourth grade, Angela and the rest of the crew are now in junior high school. Angela, who lives in Oceanside, California, has cerebral palsy and uses augmentative communication.

David Onwukwe, 5, shows his affection for next-door neighbor and best friend **Joshua Chertienitz, 10.** The boys, who live in Washington, DC, enjoy playing with toy cars and trucks on the sidewalk, splashing in Josh's wading pool and passing cookies, candy and other treats through the fence between their homes. Joshua has cerebral palsy.

Checking out the underwater creatures at the National Aquarium in Baltimore, Maryland are (from left) **Stephanie Nelson, 6, Caleb Nelson, 8, Kyle Laursen, 6,** and **Kailin Laursen, 3.** Best buddies Caleb and Kyle have achondroplasia, a form of dwarfism, and see the same doctor in Baltimore. Their parents try to coordinate the boys' medical appointments so the friends can spend time with each other during these mini-vacations. The Nelsons live in Columbia, Missouri; the Laursens live in Springfield, Missouri.

Best friends **Kelsey Welch** (left) and **Lyle Eldridge,** both 9, enjoy Lyle's birthday bash. It was no surprise that Lyle chose to celebrate his birthday at Pizza Hut—he's a big fan of Italian food! Lyle, of Montrose, California, and Kelsey, of Quartz Hill, California, have Down syndrome.

Eight-year-old Adam Malone (left) and best friend **Jimmy Dio, 6,** strut their stuff in a class production of "Sentimental Journey" at Anna McCabe Elementary School in Greenville, Rhode Island. Adam's mom, Diane, says that Jimmy can always be found beside Adam—except when he's behind him, pushing Adam's wheelchair!

Would you like to share a favorite candid snapshot or slide *of your child and/or family with other readers of* EXCEPTIONAL PARENT*? Send it to: Readers' Photos,* EXCEPTIONAL PARENT*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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Grocery Baggage

by Timothy Perry

Enjoying a quiet moment together in the car are Chelsea and Dad.

I do diapers. Lots of them. I wash dishes, do laundry and wipe runny noses. I take my daughter, Chelsea, to therapy sessions and doctor appointments. So it was no surprise—to me anyway—that this father might be grocery shopping with his daughter one busy Saturday morning at the local mega-market.

"Excuse me…" came a tentative voice from behind me in the checkout lane. I turned to see a silver-haired woman in her mid-fifties.

"I couldn't help but notice. Does your daughter have something wrong with her legs?"

Chelsea sat in the grocery cart. She was grinning wildly and sucking up eye contact like a Kirby upright, but three inches of orthopedic bracing were plainly visible to anyone who cared to look.

"She has spina bifida," I offered. "Chelsea can't really walk on her own."

I wondered if this woman would react as so many others have… by abruptly ending the conversation without uttering another word. Confronting disability turns many people instantly mute. It's an all too common response, but one to which I have always tried to be empathetic. After all, two and a half years ago, I was walking in their Reeboks.

"Oh my. She looks so… healthy. "

"She is, really!" I declared.

Chelsea is as bright, intelligent and cheerful a toddler as any I know. She exhibits none of the physiological cues that point to conditions like Down syndrome or cerebral palsy. Seated in a grocery cart, there is little to indicate she has any problem at all… unless one spots those braces.

"I'm afraid I don't know what spina bifida is," the woman volunteered, her tone suggesting a fair bit of apprehension.

Two-year-old Chelsea graciously accepts the obligatory peck on the cheek from twin brother Patrick. According to Dad, a bit of sibling rivalry has flared in the two years since this photo was snapped.

"That's OK. When she was born, neither did I. But you can bet I do now!"

So… just how much to tell this woman? We were in a short checkout lane and this could turn into a very long story. But both my wife and I had done this before—hit the high points and if they ask, deliver additional information on an as-needed basis.

I explained that a child with spina bifida is born with a hole in the spine. As a result, a lot of normal nerve connections never reach their appointed destinations. The severity of spina bifida can vary widely, from nearly total incapacitation to extremely mild physical effects. Chelsea's condition fell somewhere in the cavernous middle ground.

Then I stopped and pondered what this woman's reaction would be if I told her the whole story. Chelsea's inability to walk is but one ramification of our family's situation. I could have talked for hours about the endless surgeries, physical therapy sessions and doctor's appointments; about the medical bills—big enough to rival the GNP of some third world nations; about the fears that rage inside me like caged demons. There exists an overpowering downside to Chelsea's medical condition, but most times, I only see the upside to life with my daughter.

Significant parental bias aside,

continued on page 34

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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95 Abilities Show

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continued from page 32

Chelsea is strikingly beautiful. Once establishing eye contact with a likely victim, she locks on like a pair of vise grips. Perfect strangers are drawn to her gaze… and Chelsea had sunk her hooks into this woman from the get go.

I explained that I really felt quite thankful. Chelsea is a very happy little girl. Her condition is nowhere close to a worst case scenario and the long-term outlook is as bright as can be expected under the conditions.

"But she'll grow out of it, right?" the woman asked optimistically.

Children grow out of a great many things—colic, ear infections, teething. But unfortunately, spina bifida isn't among them.

"No, I'm afraid she won't."

"Oh don't you give up hope now! Doctors are doing incredible things these days. You never know! Maybe someday…"

Her voice trailed off as my mind revisited familiar terrain. Plenty of things can be done to help someone with spina bifida. Wheelchairs, specially-equipped vehicles and other gadgetry are available to smooth off the rough edges… but there exists no cure. Not now, maybe not ever.

"…It really is amazing to see the progress they're making. You just keep praying, okay?"

I looked into her eyes, genuinely touched by the compassion of this perfect stranger. She stood in sharp contrast to the cashier whose eyes had remained transfixed on the floor tile throughout this entire conversation.

Mom and Chelsea, 3, engage in some high-speed travel around the neighborhood.

Chelsea waits for the school bus to arrive for her first day of preschool in September 1994.

I pushed my cart forward, then turned. "Keep praying? I wouldn't know how to stop! Comes with the territory. I do diapers, too. Did I mention I do diapers? And runny noses… lots of runny noses!" **EP**

Timothy A. Perry, 39, lives in Waterford, Michigan with his wife, Jackie, and their children, Lauren, 6, and twins Patrick and Chelsea, 4, who has spina bifida and hydrocephalus. Timothy is a free-lance feature and advertising writer, producer and voice talent.

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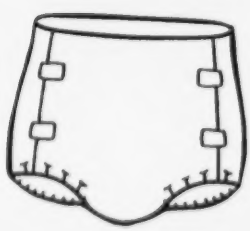

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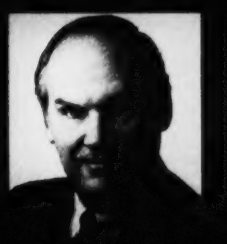

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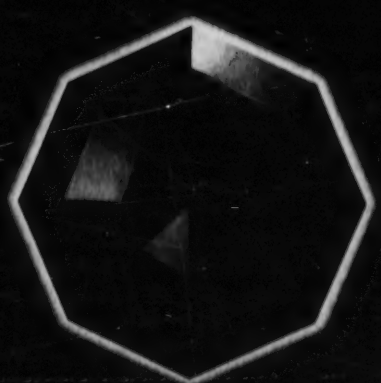


" ON "

AMERICA'S DISABILITY CHANNEL

Building Community Resources

Enabling inclusion in community programs and activities

by Serena Umstead, Kimberly Boyd and Carl Dunst

Communities can provide an extensive array of opportunities for children and families to achieve social and emotional well-being. These opportunities may include such community resources as swimming lessons at the YMCA, drop-off child care programs at local churches, library story times and soccer teams. These activities bring us out of our homes and connect us to one another.

The Building Community Resources project of the Child and Family Studies Program at the Allegheny-Singer Research Institute in Pittsburgh, Pennsylvania is developing and testing strategies to support full community participation by children with disabilities and their families. The project is working with families in two very different Pennsylvania communities. One is a small industrial town that has experienced difficult economic times; the second is a developing bedroom community on the outskirts of a major metropolitan area.

The goals of the project are to identify available programs and activities in the community, to enhance the capacity of these programs to involve all community members, and to foster enjoyable family participation in these community programs and activities—day care centers, neighborhood organizations, churches and synagogues, recreation centers, libraries, parks, pools and playgrounds, hospitals and health centers, museums, sport leagues and scout troops.

Benefits of community participation

Although many families receive support from professionals working with their children, participation in "special" programs may actually contribute to a family's sense of isolation from their community. Although the support of service providers can be valuable, families who are involved in community activities can also access support, assistance and encouragement in the same way as their neighbors. When problems arise, they can look to friends, neighbors or fellow church members.

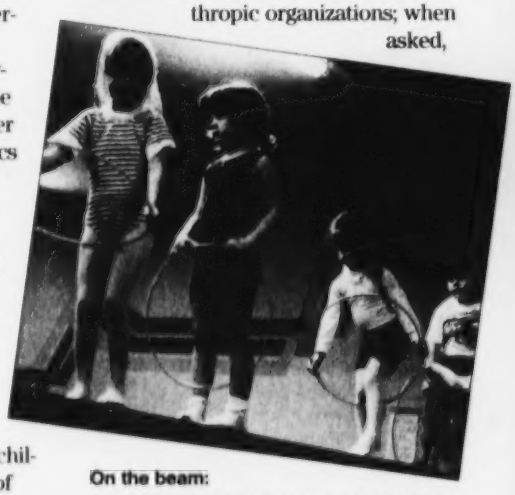
Community involvement allows families to build relationships that do not focus on a child's disability or difference. For example, one parent involved in the project said she particularly enjoyed the friendships she made while waiting for her daughter Lakeisha at swimming and gymnastics classes. She told us that when she ran into these other parents at the supermarket or mall, they had many things to talk about, including their children's accomplishments and activities.

Parents also talk about the benefits of giving other community members the chance to know their child and family. Other children come to understand that children with disabilities share many of their own talents and interests. Children who play and learn together develop respect for each other's abilities.

Making it work

The first step in building community resources is to identify or "map" community assets. This process starts by identifying your family's goals and aspirations—the experiences you would like your child or family to have. Next, identify the types of programs or activities that would meet those goals, along with the supports your family or child might need for participation. Finally, use various information resources—printed information and information provided by other members of the community—to identify potential activities and supports.

For example, the parents of an eight-year-old child with cerebral palsy were interested in swimming lessons for their daughter. Unfortunately, the pool at the local recreation center was not equipped with the lift that would be necessary to get eight-year-old Carley safely into and out of the pool. Using the mapping process, Carley's parents identified a number of civic and philanthropic organizations; when asked, one of these groups was willing to purchase the needed equipment.



On the beam:
Doug Umstead (right) enjoys participating in a community gymnastics class.

The Building Community Resources project has talked with a number of families who have a history of successfully accessing community programs for their children with special needs. We asked about the strategies they used. Here are some things they told us:

- *Finding resources*—Families often did a lot of legwork to identify appropriate programs for their children. They sometimes learned about activities through the phone book or local newspapers, but more often found out about community programs from other families and friends.
- *Providing information to programs*—Many families chose not to reveal their child's disability during the

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first contact with a program. For some families, the information they provide depends on the circumstances; many provide only the information needed to make successful adaptations of particular environments and activities.

• *The importance of "key players"*—As a general rule, successful participation in a particular activity depended on the attitude of the person having the most direct contact with the child with a disability. Many families spoke glowingly of individual swimming instructors, gymnastics coaches or preschool teachers; others spoke of difficulties encountered in similar settings but with different individuals.

The program in action

Using what we have learned from the experiences of successful families, the Building Community Resources staff helps other families explore involvement in community activities. Once a family chooses or targets an activity or program, the family decides how the project staff might help. Some families just need a few phone numbers to get them on their way; others might want to brainstorm for strategies to increase a child's participation at a local library or playground.

In such cases, the project staff mobilizes an informal community "team," bringing together the family and community members to develop and test various strategies for successful involvement. Strategies may focus on sharing information about the child, ensuring safety, building friendships, making physical adaptations or securing funding.

In the case of Carley's swimming lessons, for example, her parents and the swimming instructor were concerned about Carley's physical safety. Together they decided that an additional person in the water would be the best solution—someone who could focus specifically on Carley's safety. The last thing Carley wanted was to "stand out" by having her mother in the pool, so the team considered other people who might be available and more appropriate. As it turned out, one of Carley's favorite cousins happened to be working at the pool for the summer so she was available and happy to assist. The instructor was pleased with how smoothly the class went, and having a helper in the pool allowed her to spend more time with each child.

Focusing on similarities

The successes of the families we have worked with thus far are especially encouraging. Perhaps most encouraging is the willingness of community members and organizations to accommodate families' desires to have their children participate in community activities.

The Building Community Resources project stresses the similarities between children with and without disabilities. Focusing on similarities rather than differences places the emphasis on shared experiences. This is not to say that disabilities are ignored. Rather, supports are put into place to minimize the effects of the disability so the entire community can enjoy the benefits of shared experiences. ■P

Serena Umstead is the mother of Tenzin, 12, and Doug, 5, a child with special needs. She is a community resource coordinator in Pottstown, Pennsylvania for the Building Community Resources project of the Child and Family Studies program of Allegheny-Singer Research Institute in Pittsburgh, Pennsylvania.

Kimberly Boyd is co-director of the project. Carl Dunst is a senior research scientist with Allegheny-Singer Research Institute.

Also contributing to this article were team members Holly Shields-Menegazzi, Tina Bode and Danielle Sauer.

Inclusion at the Library

I want all three of my children to love books and enjoy reading. I have always taken my older children to the library, but I kept my youngest child, Joey, at home for the first few years of his life. Then, on one of Joey's first trips to the library, one of the librarians yelled at him, even though I was trying very hard to help him limit his loud outbursts and running.

I called the Building Community Resources team for help. They asked what I wanted; I told them I wanted that particular librarian to "loosen up." I also wanted to play a behind-the-scenes role in their initial contacts with the library. I did not want to tell the librarian about Joey's diagnosis because I thought she would only see the label and not the child. I asked that the Building Community Resources team contact the library in such a way that nobody would make an association between my child's behavior and the contact.

The team met with the children's librarian to introduce the Building Community Resources project. They offered their problem-solving services to help the library make the children's room and activities accessible for all youngsters in the community. The team also asked about strategies the library staff had found helpful for including children with differing abilities.

During this conversation, the librarian mentioned the library's concerns about including children with behavior management challenges. In response, the team was able to talk about the possible causes for difficult behaviors and offer some strategies that have proven helpful for children and families in similar circumstances.

After this meeting, the team got back in contact with me and suggested I begin a dialogue with this librarian to explain how much I value the library's programs and why I want all my children to be active at the library. Using team members as facilitators, the librarian and I began working together to find ways for all my children to use the library regularly and for my youngest child to start attending story hours. I feel really good that I was able to work things out with the librarian and that my son will be able to participate in children's room activities.

—Jody Wenzel
Pottstown, Pennsylvania

Danny Burke (right) enjoyed participating in a weekend Cub Scout campout with other members of his den.

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By Deborah M. Moss
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A true story of petit mal seizures and the hidden problem it can cause: Learning Disability
By Marian Carla Buckel and Tiffany Buckel 1994

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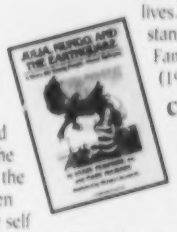
A Story for Young People About Epilepsy

By Saxby Pridmore, MD and Mary McGrath
Imagination Press, 1991



Children who have epilepsy are frequently teased and rejected by other children. This book tells the story of a young girl with epilepsy who becomes the school heroine. It addresses barriers that children with epilepsy confront and can help improve the self esteem of the child with epilepsy. Ages 6-12.

Catalog # 209QKE **$7.95**
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Dotty the Dalmatian has Epilepsy

From the Dr. Wellbook Collection
Tim Peters & Company, 1993

A delightful illustrated story for young children. This is the story of Dotty the Dalmatian who discovers she has epilepsy. At first Dotty feels embarrassed and afraid, but once she learns to accept and control the seizures she happily goes back to her important job helping the fire fighters save lives. Ages 2-6.

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"Brothers and Sisters" is divided into two sections. The first half is written specifically for siblings to read with separate sections based on age. The second half of the guide is written for parents and other adult family members (aunts, uncles, and grandparents) to help them understand and handle sibling concerns. (1992)

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Nick and his community experience a very special basketball game

A Championship Season

by Rose Gilbert

If someone had told me when I was pregnant that my son would be on a championship basketball team, I would have been proud. If someone had said the same thing when Nicholas was two, I would have cried, thinking it the cruel joke of a heartless person.

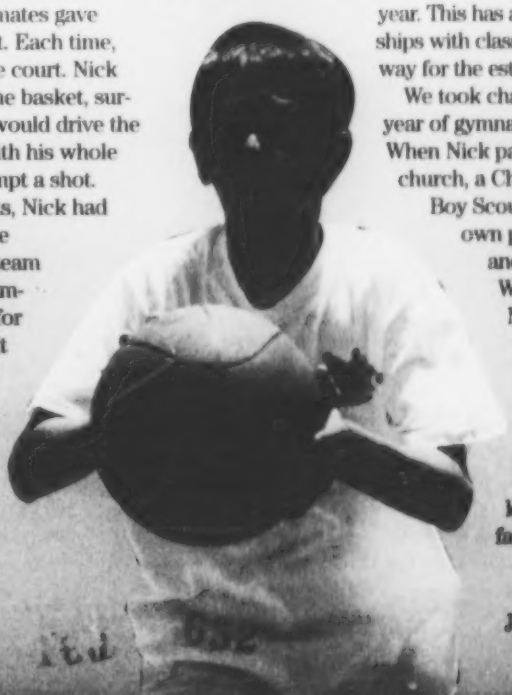
Nicholas is 14 now, but since the age of 18 months, doctors, therapists and special teachers have been a big part of his life. Nick has a severe speech disorder, mild mental retardation and mild to moderate fine- and gross-motor delays. When Nick was two years old, a doctor told us he didn't know how well our son would walk—if he walked at all. Twelve years later, although his gait is awkward, Nick walks; in fact, as a participant in the 1990 New Orleans Crescent City Classic junior road race, he ran a mile in just over 13 minutes. And, although it might have seemed an impossible dream 12 years ago, Nick has indeed played basketball with the Nuggets, a local team that won playground championships in 1992 and 1994.

A special season

The 1994 basketball season was very special. The camaraderie and sportsmanlike conduct exhibited by Nick's peers far surpassed my expectations. Whenever the team was ahead, Nick's teammates would make significant efforts to give him the ball, allowing him opportunities to make shots.

On one such evening, Nick's teammates gave him repeated chances to make a shot. Each time, they'd get the ball and head down the court. Nick stood in a designated spot beneath the basket, surrounded by his buddies. The center would drive the ball down and pass to Nick. Then, with his whole team guarding him, Nick would attempt a shot.

That night, despite several attempts, Nick had still failed to make a basket. Either he missed, or a player on the opposing team managed to block the ball. Nick's teammates moved him closer to the goal for a few more tries. Still no luck. Then it happened... not only did Nick's teammates rally around and guard him, but—quite visibly—the players on the other team backed off, allowing Nick time to set up and try for the shot. When the ball swished through the net, not only did Nick's team cheer and applaud, so did the other team, all the players on the benches and all the moms and dads in the bleachers.



Years of exposure

How did this happen? How did an entire community reach the point of being able to show such unselfish support to a member with a disability? It didn't happen just during that one game or one season. It took all 14 years of Nick's life—years of exposure to the community, years of living and going to school in our neighborhood.

Mike and I have always seen Nick as a child who just happened to have a disability. Although our dreams for Nick were severely altered, we never stopped having expectations for his behavior and his participation in the community.

We have used the everyday activities of our lives to teach Nick independence. Grocery shopping, banking and even voting offered Nicholas new opportunities for learning in the community.

Each year, we have adjusted his daily school schedule to include more or different opportunities for Nick to be around peers without disabilities. Furthermore, we have negotiated with the school system to keep Nick with the same group of students from year to year. This has allowed him to develop close relationships with classmates, relationships that paved the way for the establishment of very natural supports.

We took chances. Before basketball, there was a year of gymnastics and a few seasons of track. When Nick participated in the AWANA Club at our church, a Christian boys and girls program like Boy Scouts, he was allowed to move at his own pace and receive appropriate support and adaptations in earning badges.

When he started playing basketball, Nick was allowed to play on a team of younger players. Nick wasn't always readily accepted, but we kept exposing the community to the challenge of our differences and expectations.

No, that special night on the basketball court didn't just happen. The families in the bleachers and the

continued on page 40

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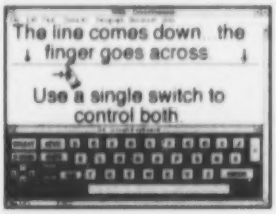

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Circle #80

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young boys on the basketball court had known Nick for years. They'd attended school with him, and seen him at the bank, at the grocery store, at McDonald's, at church, at the gym and throughout our community.

Life lessons

Months after basketball season ended, I was waiting in line at a fast food restaurant when Nick turned to a stranger and said, "I 'member you!" This "stranger" turned out to be the mother of one of Nick's teammates, the boy who always set up the shots for Nick. She conversed with Nick for a few minutes, then turned to me and told me how special she thought those games had been.

Another mother shared what her son had said about the night his team, several points behind in the game, had relaxed their guard and allowed Nick to keep trying until he made that basket for the opposing team. "Mom," he'd told her, "that was the hardest thing I've ever done." But just think of the life lessons those boys were learning that night!

Joining Nicholas for a backyard basketball game are (from left) cousin Danny Porter, Nuggets teammate Chester Schwall and Sunday school friend Jonathan McGee.

We would advise other families to hang in there, take chances and be realistic. We continue to work toward our goal of independence for Nick. Each year of school and community involvement has built on lessons learned the year before. As always, we continue to focus on Nick's strengths—his strong sense of direction and love of people. The successes we've experienced thus far have been grounded in these strengths. **EP**

Rose Gilbert lives in Harahan, Louisiana with Mike, her husband of 18 years, and their two sons, Nicholas, 14, and Aaron, 4. Rose is director of Families Helping Families of Greater New Orleans (FHF of GNO), one of a network of nine family-directed resource centers in the state. Rose has also been co-director of Project PROMPT, Louisiana's Parent Training and Information Center, a program of FHF of GNO.

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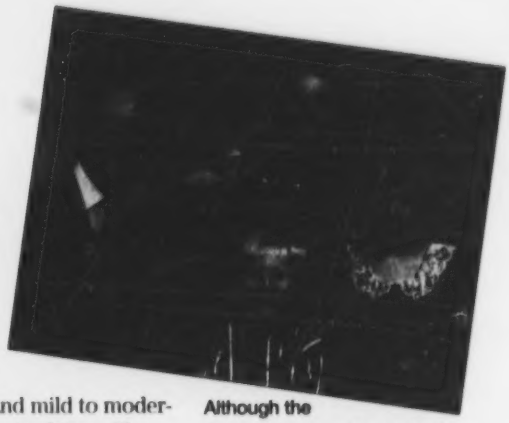
Respite Care
and the Religious Community

by Bill Van Dyken



Although the Gabhart family—(clockwise from left) Dean, Laurie, Jeff, Katie and Tim—was new to their congregation, 15 volunteers came forward to provide respite care for Katie, who has Sotos syndrome.

I remember well the astonished response—"Do you mean someone from our church would actually call and invite my child over to their house?"

"Yes!" I replied with certainty. The mother's face brightened, and then saddened.

"No, I don't think so," she said softly. "No one from our church has ever asked our son over. In fact, I really don't think anyone cares."

I think about those words of resignation every time I hear of a family who has a child with a disability and needs community help to give them some time off from the demands of caring for their child. These words are far too common among families who have been faithful members of their religious group, but feel lonely and abandoned by their faith community. I can sympathize with the family who desperately needs help—we, too, have a child with a disability. But because I am a pastor, I can also identify with people in the faith community who at times may seem unhelpful and uncaring.

Kathy Schreurs (right) describes her first experience with respite care as a "disaster." Now, she is one of Katie's favorite caregivers.

People in the religious community do care, but they sometimes lack the knowledge or organizational skills to carry out that care. Yet, with the right promotion, urging and organization, religious communities can provide respite care in an effective way.

In the last five years, I have worked with 20 different religious groups to set up respite programs. Out of those 20 programs, about half are still operating.

Of course, situations change—people move and other avenues of respite open up, such as government-funded programs. For the most part, however, the longer-running programs are those that have an active committee in the congregation continuing to monitor and promote respite care.

Organizing respite for Katie's parents

Dean and Laurie had not been in town very long, but had heard about a program for family respite. Their daughter, Katie, has Sotos syndrome and mild to moderate mental retardation. She needs help with dressing, toileting and eating. Katie's parents responded to a survey indicating that they would be interested in respite care through their faith group.

Ron, the couple's pastor, was more than willing to be involved in recruiting volunteers and helping with the necessary organization of the program. I offered to help him by speaking to potential respite providers. Fifteen possible volunteers attended the first organizational meeting. Laurie later commented, "As relatively new members of the church, we were overwhelmed by the response and encouraged by the willingness of people to help us out."

Before the organizational meeting took place, I asked Pastor Ron if he knew of someone who would be willing to coordinate the program. Church member Pam Wright agreed to take on that role. Her job would be to phone volunteers and send out written reminders before each respite visit. This was to occur twice a month initially; if there was a need for additional respite, Dean and Laurie could ask for more help.

At the organizational meeting, we spent most of our time talking about what it means to take care of Katie. Her parents and teacher shared their insights on Katie's needs. We discussed Katie's habits, likes and dislikes and ability to adjust to new situations. (Katie's medical needs were minimal, but in other cases, it may be helpful to invite a medical professional

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Volunteer Lorraine Roorda (left) admits to some initial reluctance to volunteer for the respite program. But with the encouragement of husband Hessel (right), she gave it a try. Now she says, "My confidence in caring for a special child has grown. I have the satisfaction of doing something to give Katie's parents a short break, and I have gained some new friends as well."

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Steps to a Successful Respite Program

• **Compile a mailing list:** Work with local agencies to compile a mailing list of families who have children with disabilities.

• **Determine community interest:** In cooperation with cooperating agencies, send out a survey asking parents if they would be interested in respite care through their faith community.

• **Provide details:** Tell interested parents about the use of volunteer respite providers in religious congregations. Explain that recruitment of these volunteers and a program coordinator will be handled through the religious group, but that they have the final say regarding choice of volunteers. Ask permission to contact their faith leader.

• **Inform faith leader of family's need for respite:** Tell the leader of the family's congregation about the use of volunteers as respite providers. Ask him or her if there is an existing group in the congregation that might be willing to take this on as a project.

• **Develop recruitment strategies:** With faith leader or working group, decide on the best way to recruit volunteers. Ideas may include bulletin announcements (if parents feel comfortable with this approach), personal appeals and speakers—parents from other congregations who are current respite users may be especially effective speakers.

• **Find a program coordinator:** Get someone who is compassionate, available for calls and, preferably, unrelated to the respite-using family. The congregation's secretary or a senior citizen who is usually at home and near the phone may be ideal for this role.

• **Set up an organizational meeting:** Do this after at least six potential volunteers have signed up. Have volunteers meet with the parents, the child and, if appropriate, educational and/or health care professionals. It is helpful if a child's parents and other professionals can provide written information about the child that can be distributed to volunteers.

• **Set up guidelines with parents:** Make note of the times, places and frequency of respite the family is seeking. Remind parents to go through coordinator for all respite needs.

• **Set up guidelines with program coordinator:** The coordinator will make all respite arrangements. If parents have need for additional respite, the coordinator can make arrangements with volunteers. Have coordinators send reminders to providers before each scheduled respite time. Make sure all respite providers have the coordinator's phone number.

• **Promote congregational awareness:** It is important that the religious community feel a sense of "ownership" of the program. An article in the faith group's publication, notes of appreciation to respite providers and public mention of the program from the faith leader contribute to congregational awareness and this feeling of ownership.

• **Evaluate program:** Evaluate a new program within the first three months. After that, do it every six months. Check with the parents and the coordinator to see how well the process is working.

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to the organizational meeting to provide an overview of a child's medical condition and special needs. In some cases, respite volunteers may need to learn special techniques to care for a child with complex medical needs.)

We talked about the need to start slowly with Katie, letting the newness of these visits be short. We also spoke about where respite care should take place—a decision that needs to be made by individual families. Katie's family decided that she should be cared for outside of the home; this would allow Dean and Laurie to spend more time with their other two children.

Positive experiences for volunteers

A few volunteers will eventually become "favorites" for the child and family. Katie is particularly fond of Kathy, but this did not happen overnight. In fact, Kathy recalls her first official respite experience as "a disaster"—"When I went to pick Katie up, she clung to her father and was very emphatic about not wanting to go out with me. 'No!' is a pretty clear word. Katie was upset, her father was embarrassed, and I was devastated."

It took Kathy some time before she felt ready to try again. But after a few visits with the entire family, including a trip to an ice cream parlor, Katie decided outings with Kathy might be fun. Now they regularly enjoy a variety of activities together—attending basketball games, going to the mall, baking cookies and feeding Kathy's guinea pig.

Lorraine, a 70-year-old grandmother, was initially reluctant to be part of the respite program. She remarked, "Even though I had a desire to help, I decided I was not capable of caring for Katie." But when Lorraine's husband offered encouragement, she decided to give it a try. Now Lorraine reports, "This has been a good experience for me. My confidence in caring for a special child has grown. "

Responses from other volunteers have been equally positive. Arlet, a special education teacher, commented, "Being involved in the respite care program with Katie has given me a way to use the abilities God gave me and help friends in the process."

Kids also benefit

Respite not only gives parents a much-needed break; the program may also provide their children with socialization experiences. As Dean and Laurie put it, "Respite has allowed Katie to experience more and varied social situations and to become more accepted as a member of the church and community."

When I hear discouraging words from parents who have given up on their faith community, I think about the words of other parents such as Derrick and Marla who wrote: "We have greatly appreciated the respite program through our church. The members of our respite team are very willing to help us out when needed and seemed to have gained as much as we have in building a relationship with our family." **EP**

Bill Van Dyken is an ordained pastor and chaplain in the Christian Reformed Church. Since 1987, he has been religious services coordinator at Hope Haven in Rock Valley, Iowa. Hope Haven, a rehabilitation and housing agency, has served people of all ages with intellectual impairments for more than 30 years.

Bill edits Pastor to Pastor, *a quarterly newsletter for area churches. He is a board member of the Christian Council on Persons with Disabilities. He and his wife, Barbara, live in Rock Valley with twins Matthew and Lora, 16. Their oldest son, Mark, is married and lives in Fort Wayne, Indiana.*

The Power of Love

A "package deal"—On their wedding day, Teri and Bob Mika pose with their ready-made family, sons Matthew, 6, and Brandon, 4.

When Bob and I got married, he knew he was getting a "package deal." Along with me came my sons—Matthew, a lively, verbal six year-old who loves to be the center of attention, and Brandon, 4, who has been diagnosed with pervasive developmental disorder (PDD) and autistic tendencies. We thought we knew what we were getting into, but neither of us was prepared for the amount of adjustment it would take to become a "family."

"It's just going to take time," we told ourselves. But within a few months, we realized things were getting worse instead of better. Bob felt rejected by the boys and neglected by me. I was overwhelmed; I felt like I was taking on responsibility for all the relationships in the house. I was constantly exhausted from work and worry. The boys were showing their frustration with our awkward first attempts at parenting together.

We first heard about the respite program through our area education agency. Initially, the thought of asking for help filled us with apprehension. When Pastor Bill spoke to our congregation and asked for volunteers, I was sure the sign-up sheet would stay empty. Then we found out that 12 families had volunteered! We were relieved and filled with joy; we were being heard and understood instead of judged. Just knowing that other people were willing to help did a lot to make us feel better about ourselves as a family.

The program has worked well for us. Each volunteer family is different, so we ask what they feel comfortable doing the first time. Some begin by coming to our house to ask questions and meet Brandon. Others seem comfortable just "taking the plunge," so we go ahead and drop Brandon off for a visit. So far, every home has had something to spark his interest—an interesting video, a dog, pigs, cows, pizza or a person with blonde, straight hair (a special favorite with Brandon).

The respite program gives us the chance to attend a support group once a month without having to find a sitter who "can handle" Brandon. Volunteers will also take Brandon just to give us a break or allow us spend some time with attention-starved Matthew. And a few families have gone beyond the call of duty and cared for both boys, giving Bob and me some much-needed time with each other.

We're so thankful for these people who so willingly give their time and love to our son. We were initially surprised that our church was so open to this program, but we have come to realize that we can never underestimate the power of love in God's people.

—Teri Mika
Inwood, Iowa

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Community

Integrated Neighborhood Playgroups

Creating an environment where friendships can blossom

by Trudy Marsh Grable

I can vividly recall the sunny, warm and heartbreaking Sunday afternoon that I started my first journal. I had heard others say that keeping a journal is therapeutic, and desperate to rid myself of the frustration and sorrow I felt, I purchased a blue, paisley print, hardcover "blank book." Eager to begin this ten-dollar therapy, I put pen to paper and began writing—awkwardly at first—about my feelings and difficulties as I worked at the daunting task of integrating my little blonde beauty into our world.

My daughter, Lauren, experienced her first seizure at three months of age. It was not to be her last. She was eventually diagnosed with an epilepsy syndrome known as Lennox-Gaustaut, along with developmental and language delays. Her behavior was unpredictable, impulsive and often invasive. The neighborhood children who came into contact with Lauren were hesitant and sometimes fearful of her unpredictable nature.

On the day of my first journal entry, I felt particularly defeated. It was the second or third time I had taken Lauren to Sunday school. Katherine, the Sunday school teacher, was very willing to include Lauren in the class; I'd stayed to assist her. Sadly, it became apparent to me that this was not working. Due to Lauren's disruptive and distracting behavior, I needed to remove her from the classroom repeatedly. I recall standing outside with Lauren, peering through the classroom window and praying that she would someday acquire the skills I saw developing in the other children. Although this group of children was one to two years younger than Lauren, the developmental gap seemed insurmountably vast. I left, feeling hopeless and heartbroken.

At home, I wrote in my new journal—"I think I will start a neighborhood playgroup." I never could have imagined the sequence of events that would follow—or their positive impact on Lauren, our family and our neighborhood…

Getting started

I had no road map for beginning this venture, but I forged ahead. Although Lauren did not play with other children, I knew she needed socialization and exposure to the behaviors of typically-developing children. Other mothers become Girl Scout leaders for their daughters; I became a playgroup facilitator so that my daughter could participate in her community.

I decided the playgroup should meet on Friday mornings. I began by inviting two neighborhood children, one boy and one girl, both younger than Lauren. To their parents I explained my motivation and plans for the group. Another neighbor, Sherry, provided child care for neighborhood children; she became a great resource for identifying additional children to include. When one of our regular kids became ill and unable to attend, I would invite one of the children at Sherry's. Eventually, they all became regular members of our group. On school holidays, we would invite their older siblings to join us. They became my "helpers."

The fear of failure was especially present in the early weeks of Lauren's playgroup. Not every session went smoothly. This would make it difficult to prepare for the following week. But my fears slowly resolved as I began to realize that the sessions, no matter how I felt about them, were well-received by the children.

During the first meeting of the neighborhood playgroup, participants (from left) Sam, Tracy and Lauren work on an art project.

Growing pains

My biggest challenge was to watch the developmental gap widen between Lauren and the other children. It was never easy to watch the younger children's abilities surpass Lauren's. Many times, those feelings made me think about bringing the group to an end.

I was forced to reexamine my goals—this group was for Lauren, not for me. No matter how I felt, I had to realize that the benefits Lauren was receiving from the playgroup greatly outweighed the sense of loss I sometimes experienced.

In a way, the playgroup helped me to become more accepting of Lauren's differences. This was not easy. Initially, I would try to encourage Lauren to imi-

tate the behaviors of the other children. I hoped—somehow—they would not notice she was "different." When Lauren went into "tantrum mode," throwing herself to the ground in front of the kids, I would think, "My God, they are going to notice!"

It took some time to let go of the tendency to try to make Lauren appear "like them," just as it took time for the other children to accept and understand her differences. It's funny—as I write this, I realize the kids were way ahead of me in this respect.

A sense of belonging

We continued to "play"—first on Fridays, then on Saturdays—for nearly four years. Three years after the playgroup began, we moved from the neighborhood, but many of the original participants remained involved with what I called our "playgroup," and what Lauren described as "the kids coming."

"Circle time" offered an opportunity for a variety of social activities including sign language lessons and discussions about disabilities. Participating in circle time during the first year of the playgroup were (from left) Sam, Kelli, Becky and Lauren.

"Arts and crafts" activities lent themselves quite naturally to individualization. Different children could work on different activities during the same art session. And children with more advanced skills (like being able to use scissors) were able to help younger or less-skilled children.

Lauren's participation in the playgroup provided her with a sense of belonging. Neighborhood children now greet her enthusiastically. Before the playgroup, these same children headed in the opposite direction upon her approach. Lauren is now a welcome participant in most activities. Through our community's acceptance of our daughter, our entire family has developed that same sense of belonging.

As for me, I have thoroughly enjoyed my role in the lives of these neighborhood children. The playgroup has provided me with an opportunity to see my daughter in a situation that fosters success and belonging. Friendship is a dream we have for all our children; the playgroup became the tool for my "special" child to achieve that dream. As unnatural as it may seem, there are times when we have to *create* environments in which friendships can develop.

Lauren is now in a school setting that meets her academic and functional needs and makes a significant contribution to her social skills through inclusion opportunities. Her teacher shares my vision of the gifts our children can offer their peers without disabilities. Her belief in inclusion has rekindled my dream for Lauren's full inclusion.

Two years ago, I wrote in my journal:

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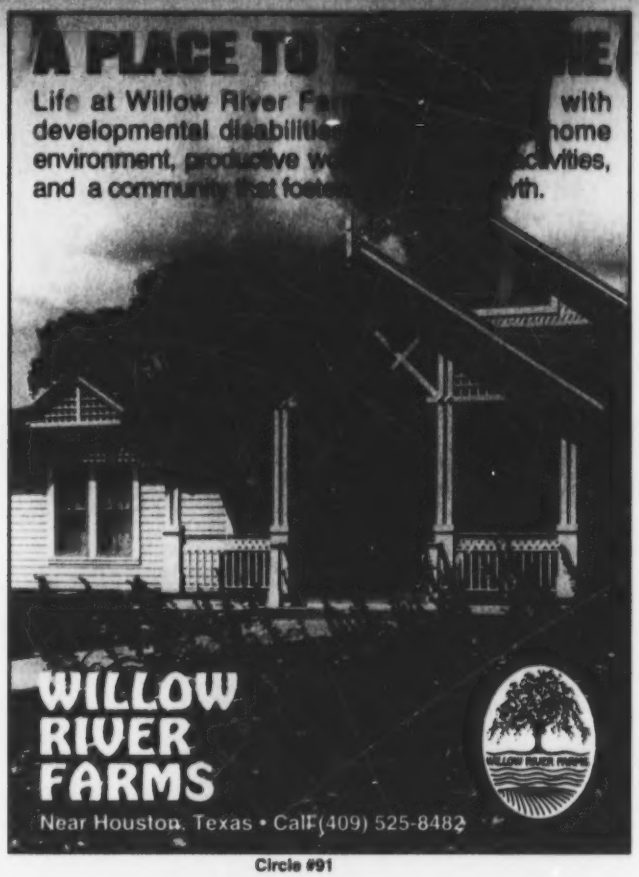
Tips for Creating a Successful Playgroup

- *Start with a small group.* An initial group of no more than three children, including your child, is a good beginning. If appropriate, you can invite additional children to participate at a later date.
- *Explain your child's disability to other parents in as much detail as possible.* Do not assume that they already understand your child's condition; even close friends may be cautious about asking questions. Once parents have some details, they become capable of answering questions their child may ask at home.
- *Set a regular day and time to meet.* This allows the parents of your participants to plan their schedules and increases the likelihood of regular attendance. It also gives you time to prepare for each session—both physically and mentally.
- *Prepare a schedule of activities for each session.* Having a schedule allows you and the children to have expectations and gives the day some definition. It will also come in handy when one of the children does not want to leave an activity; you can refer to the schedule and say, "Look, the schedule says it's time to do this now."
- *Create opportunities for your child to shine.* Perhaps your child has mastered a skill and can assist another child. This will provide other children with another view of your child's capabilities.
- *Design activities in a way that allows everyone to experience success.* For example, some children can practice writing their names while others trace theirs or just practice holding a writing instrument.
- *Incorporate your child's IEP goals into your program.* A playgroup offers invaluable opportunities for your child to see his or her peers "model" desired behaviors. For example, your child may be working on her IEP goal of tracing a straight line while other childre are tracing letters, writing sentences or practicing cursive writing.The important thing is that all the kids are holding crayons, pens or pencils and writing on paper.
- *Promote socialization by pairing children to work together, and by having one child assist another.* When pairing children, be prepared to assist them with "cooperation skills."
- *Keep notes, project samples, pictures and videotapes of the group.* This helps you measure the progress of your group. Your child may enjoy watching the videotapes—Lauren does! You may also want to show them to parents of new children you would like to invite to your group.
- *Take time off when needed.* If you feel burned out for longer than a few hours after a playgroup session, you may need to examine your schedule and activities, or consider hiring a helper. Teens can often fill the helper role.
- *Be kind to yourself.* Developing a group takes time, effort and commitment on your part and the part of others. A playgroup evolves over time and through the development of relationships between you and the children. Think of yourself as the conductor of a new group of musicians; it takes time to create harmony in the symphony



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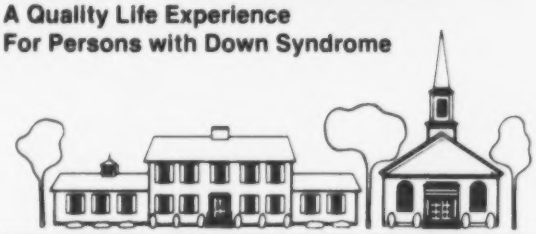

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Circle #161

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"Perhaps, in the near future, our children will remain where they belong—in their communities, developing natural bonds at neighborhood schools, in their front yards and at Girl Scout meetings; and their lives, along with the lives of their families, will be one of inclusion, not exclusion."

As parents, we can be the driving force to create this opportunity for our children. Through partnerships with friends, neighbors and spouses, a playgroup may be the start of community inclusion for your child. **EP**

Taking a break during a 1994 nature walk are (clockwise from left) fourth-year playgroup participants Jessica, Lauren, Rachel, Becky, Andrew and Elizabeth. The children used the "neat stuff" they collected during their walk to make a collage.

Trudy Grable lives in Saratoga, California with her husband, Martin, and children, Heather, 21, Nicole, 17, and Lauren, 10. Trudy is the director of technology resources at PHP—The Family Resource Center in Santa Clara, California, where she is also sysop (systems operator) for the LINCS BBS (electronic bulletin board; 408/727-7227, N-8-1, up to 14,400 bps). Her Internet e-mail address is trudy@php.com.

Trudy is the author of WHERE DO I BEGIN? INTEGRATED NEIGHBORHOOD PLAYGROUPS, *a manual to assist parents in developing their own neighborhood playgroups. (See below for ordering information.) This article has been adapted from a portion of that manual.*

Want to learn more?

WHERE DO I BEGIN? INTEGRATED NEIGHBORHOOD PLAYGROUPS by Trudy Marsh Grable is a practical, easy-to-read, 85-page manual for developing a neighborhood playgroup that will meet the individual needs of your child and family. Included are suggestions for selecting participants, planning successful activities and handling questions and conflicts. To order, contact PHP—The Family Resource Center, 3041 Olcott St., Santa Clara, CA 95054-3222; (408) 727-5775; e-mail: inp@php.com. A $15 donation is suggested (all proceeds benefit PHP's Family Emergency Fund).

With Trudy acting as the trainer, a playgroup training program is available within the state of California. These day-long workshops have been developed through a small grant from the California State Department of Developmental Services. Contact PHP for more information.

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TAKING

Irene Pollin, author of TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS, *is a parent and psychiatric social worker. In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope with long-term effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed. After the loss of two of her own children, Pollin returned to school for training as a psychiatric social worker.*

Although TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS *was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members. Here's what nationally-syndicated columnist Ann Landers says about* TAKING CHARGE: *"[This] book... should be required reading for everyone facing the challenge of long-term illness, whether their own or that of a loved one... It could be the most valuable gift you will ever give."*

In Pollin's words—"I have discovered that by confronting and taking charge of your fears, you can learn to accept your [or your loved one's] long-term condition. Indeed, you can once again take charge of your life. This book will show you the way." TAKING CHARGE *is available from Exceptional Parent Library (800/535-1910). The following is an excerpt:*

Feelings You Might Want to Share

You may believe that your family cannot understand you because they're not sick. I have found, however, that although they can't identify with you completely, they can be supportive if you let them know what you're thinking. You might want to share the following emotions and needs with your family to spur open communication:

- Tell them that you don't expect them to solve your problems. You just need them to listen and be supportive.
- Tell them that you feel like a burden on them and need reassurance that they don't mind giving the extra attention you require.
- Tell them that you know they sometimes feel trapped by the illness and by you.
- Tell them that you have thought a lot about it and often feel the same way they do; you are all victims of your disease and the position it has put you in.
- Describe to them the kinds of support you need from them. If you want space and time alone, ask for it. If you need them to be around more, ask for that too. (This may not always work perfectly but it's better than not expressing your desires.)
- Let them know that you miss going places (like sporting events or concerts) with them that have become difficult for you to manage. Help them find alternative activities you can all enjoy or if you are too incapacitated to attend an event, encourage them to go with someone else.
- Tell them that you understand that they're not angry at you, but at the situation, so they need not feel guilty.
- Reassure them that you understand their feelings—they aren't too different from yours. You're in this together.
- Guide them on how to treat you: with sympathy, empathy, or support while honoring your independence and your feelings.
- Let them know how important they are to you. You need them and you need to be needed.
- Tell them how much you appreciate all that they're doing for you, even if they can't meet your expectations. (In fact, given the circumstances, you might have to reevaluate those expectations.)
- Ask how they feel about talking about your illness; do they fear being hurtful towards you? What subjects does it hurt them to bring up and what ones are all right to bring up? (Be sensitive about how much they can tolerate.)
- Ask if you're being unreasonably demanding. Back off if you are!
- Ask if they need time off. If they do, tell them that you understand their needs and want them to have respite.

Watch for the danger signs of burnout, such as withdrawal and short tempers or anger directed at you. You can suggest family counseling if you feel that tension is building and you don't know how to handle it. A minister or rabbi, hot-line volunteer, self-help group, good friend, or professional counselor can help in times of difficulty.

Reprinted with permission of Times Books, a division of Random House, Inc., from TAKING CHARGE, *© 1994 by Irene Pollin.*

CORRECTION: The excerpt from TAKING CHARGE, *that was published in the June 1995 issue, featured a picture of a different book with the same title.* EXCEPTIONAL PARENT *regrets the error.*

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Why Parents and Children with Disabilities Should Have the Right to Use Facilitated Communication

by Douglas Biklen

In the mid 1970's, Australian educator Rosemary Crossley rediscovered a method of communication that American teacher and parent Rosalind Oppenheim had used as early as the late 1950s and had written about in her 1974 book *Teaching Methods for Autistic Children*. The technique, which Crossley named facilitated communication (FC), involved providing physical and emotional support to a person with a developmental disability (such as autism, cerebral palsy and Down syndrome) and limited or no speech. This support enabled the person to point reliably, and thus to communicate by pointing at pictures, at whole words or at letters to form words. Crossley first used FC with Anne McDonald, a girl with cerebral palsy living in an institution for children with multiple disabilities, all of whom were presumed severely retarded.

The method is intended to help individuals overcome problems of voluntary physical movement including finger isolation (for example, the ability to extend the index finger while keeping the other fingers folded under the palm), tremor, hand-eye coordination and initiation of action (the ability to begin, continue and stop a movement).

Lucy Harrison, 18, uses a typewriter while her mother, Nita, facilitates with one hand on Lucy's shoulder. Lucy began using FC in 1990, and was initially facilitated with wrist-level support.

Controversy over authorship

Controversy over the method has to do with whether facilitated messages are authored by the person with the communication impairment or by the facilitator.

Anne McDonald proved her communicative competence to the satisfaction of the Victorian Supreme Court by typing "string" and "quit," after the words "string" and "quince" were given to her by the presiding officer while her facilitator, Crossley, was out of the room. A court-appointed psychologist also had Anne take a Peabody Picture Vocabulary Test, in which she selected from a set of four pictures the one that illustrated the meaning of the word said by the examiner. She was able to accomplish this task independently, that is, without physical support. Her score on the test was within the range expected for a person her age. McDonald has since completed a Bachelor's degree and is currently enrolled in a Master of Arts degree program.

However, the first formal, published FC validation study (a study to determine whether FC is valid communication) produced results that left many observers in a quandary. In this study, done by the Victorian state [Australia] government, three FC users were asked to describe gifts their facilitators had not seen; three others were asked to reply to questions different than those given the facilitators. Although the study showed that the method worked for some people, it also revealed evidence of facilitator influence on communication.

Studies raise skepticism

Criticism of FC has been harsh, fueled by the results of numerous controlled studies in which people using FC have failed to validate their communication. In the first, conducted in 1992, 12 individuals classified as autistic were shown colored pictures of familiar objects and asked to name them. *None* of the individuals gave correct responses when shown items different than those shown to the facilitators. However, in two instances, individuals did name appropriate categories for the items they were asked to identify—responding "vehicle" instead of "van," and "food" instead of "bread."

Numerous subsequent studies seemed only to confirm these results. In one study after another, individuals were shown pictures that their facilitators could not see, or were asked questions that their facilitators could not hear, and they did not respond correctly.

Validation under controlled conditions

It did not surprise me that people did so poorly on the early tests. Being observed or tested may cause individuals to perform more poorly than usual. Moreover, none of the early studies gave participants the chance to practice test-taking. In each case the tests were done in one or two sessions.

Several recent studies, however, *have* revealed authorship by people using FC, although at the same time noting the presence of facilitator influence. Dr. Carol Vazquez conducted a study in which one individual was able to describe a video his facilitator had not seen and another was able to identify

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objects that her facilitator could not see. Vazquez concluded, "...erratic in their performance, each subject was able to report information unknown to the facilitator in one out of four controlled sessions."

Elliot Simon and his colleagues asked FC users to report on activities in which they had engaged—such as getting snacks from a vending machine and visiting the library. The researchers found that "for some students there is evidence of authorship for information unknown by the facilitator." But the researchers also determined that facilitators could influence individuals' communication. In light of these findings, these researchers strongly advised pursuing the goal of independent typing, a goal I had also advised in my book, *Communication Unbound.*

In a 1993 study, Ogletree and his colleagues evaluated a four-and-a-half-year-old's communication abilities. Without FC, the child was judged to have the communication ability of a six-month-old. With FC, he produced words—often misspelled or spelled the way they sounded—and described activities about which his facilitator was kept unaware—for example, blowing bubbles, playing with water and swinging. In conclusion, these researchers called for "an open but objective posture regarding the method's use with persons with autism."

A year-long government study in Queensland, Australia, published in 1993, found that 87 percent of the 24 clients evaluated were able to validate their communication through responses to questions about their activities—for example, asking a person to report on a gift received while the facilitator was not present or to report on piano playing about which the facilitator was unaware. About half of these individuals were also successful in answering multiple-choice tests in which the facilitator did not know the answers (such as names of family members).

The largest study of FC to date has been carried out in the California public schools by Donald Cardinal and his colleagues. Their unpublished study (currently under review by a professional journal) included more than 3,800 trials, more than all of the above-mentioned studies combined. Students classified as "severely disabled" were asked to spell randomly-selected words that they were shown while the facilitator was out of the room. They were asked to spell five words per session, in three sessions per week. By the end of the six-week study, 74 percent of the students were able to correctly spell one or more of the words shown to them by the tester while the facilitator was out of the room; half were able to spell at least two of the five words. On average, students reached their peak performance at this task after nine sessions. The re-searchers concluded that their test validated communication when many others had failed because the length of the study allowed students to practice the test activity—though not the actual words—and because the activity occurred under natural conditions, as part of the regular school day. For each word typed, researchers estimated that there was no more than a one-in-one-hundred chance that the facilitator could guess the word correctly.

At Syracuse University, we have two controlled research studies underway in which FC users are proving their communicative competence. Both studies show that people are often able to succeed with validation tests if they have opportunities to practice the type of test activity and if the task accommodates particular difficulties such as word retrieval.

Nearly everyone has difficulty with word retrieval—for example, when we cannot think of the name of someone we see during the day, even though we may typically be able to recall the correct name some time later. Many people who use FC seem to have extreme word retrieval difficulty, even for naming obvious objects. In testing, one strategy to avoid word rerieval problems is to provide multiple-choice answers; this allows the correct answer to be available for selection.

In our current studies, individuals have taken several sessions—in some cases, as many as eight sessions—before succeeding with validation tasks. Nearly all of these tasks include multiple-choice options or other tasks that do not involve word retrieval—for example, unscrambling letters to form a word or completing math problems.

In light of these studies, reasonable people must admit that some individuals who were previously believed incapable of literate communication have demonstrated that under the right conditions, they are able to convey their own thoughts via FC.

Independent typing

The goal of FC is independent typing. Many people using FC may be able to reach that goal. Rosemary Crossley and her colleague, speech pathologist Jane Remington-Gurney, report that more than 30 individuals with whom they had worked in Australia are now typing independently. In North America, there have also been reports of substantial progress in typing ability, including independent typing.

At the 1994 annual conference of TASH (The Association for Persons with Severe Handicaps), I presented videotapes of two individuals typing without any physical support; each had first learned to communicate with facilitation. Both were previously believed to be severely retarded, but have since demonstrated excellent literacy skills.

Again, reasonable people must admit that individuals who learn to communicate with facilitation and then achieve independent typing have demonstrated the ability to communicate their own ideas.

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To learn more...

- **Communication Unbound,** by Douglas Biklen, focuses on how FC works, the controversy, ways of confirming authorship and implications for understanding disability and ability. Published by Teachers College Press, Columbia University (PO Box 2032, Colchester, VT 05449, 800/488-2665; $17.95 plus $2.50 handling).
- **Under Controlled Conditions: Validating Facilitated Communication** (video, 23 min.) documents a study in which people using FC learned to validate their communication while playing computer games. Every Step of the Way: Toward Independent Communication (video, 20 min.) shows how individuals using FC have begun to achieve independent typing. Available from the Facilitated Communication Institute, Syracuse University, Syracuse, NY 13244 ($50 plus $2.50 handling).
- **I Don't Want to be Inside Me Anymore: Messages From an Autistic Mind,** by Birger Sellin, is an autobiographical account of autism, written through FC. The book was written by a teenager in Germany, where it sold more than 50,000 copies. The English translation was published by Basic Books in 1995 ($22, may be ordered through local bookstores).

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Allegations of abuse

There have been concerns about allegations of abuse made through FC. The only scientific investigation of this issue was conducted by pediatrician Ann Botash and her clinical team at a Syracuse, New York hospital. When any child makes an allegation of abuse, a hospital team examines the case to see if there is any other "indication"—other than the allegation—to suggest that abuse might have occurred. Other "indications" of abuse might include physical evidence, a confession by the person accused or confirmed abuse of other children in the family. Botash's team examined all abuse allegations made through FC that were evaluated at the hospital over a three-year period, a total of 13 cases. The study found that other "indications" of abuse were found in 47 percent of these cases, the same percentage as in cases where allegations were not made through FC.

In addition, two recent court cases have upheld the right of an individual to use FC in court proceedings. In one case, a coworker of the accused said that the defendant had admitted his guilt during a private conversation outside of court.

In *any* instance of alleged abuse made through FC, there must be extreme care to assure that the FC user is the author of the allegation. I have consistently recommended a simple procedure—bring in a second facilitator who is unaware of the first allegation to see if the person can repeat his or her statement.

Ethical concerns

Given these findings, I strongly endorse the position taken by TASH: that no parent or person with a disability should be denied the right to use the method of communication of his or her choice, that no person should be denied access to basic rights—including the right to appear in court—on the basis of his or her communication method, and that validation of communication ability should always be discussed with the person who uses FC and should include multiple strategies attempted over long periods of time.

The latest research evidence on FC and the achievements of individuals using FC require us to ensure its future availability. It is not a miracle and it certainly will not work for everyone, but those who might benefit from it deserve the right to learn to use it, to type out their words, to be heard, to prove their communicative competence and to be recognized for their accomplishments. **EP**

Douglas Biklen, Ph.D., is professor of cultural foundations of education and director of the Facilitated Communication Institute at Syracuse University, Syracuse, New York.

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Circle #22

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CONNECTIONS

The Newsletter of the National Center for Youth with Disabilities

A Transition Success Story:

Collaboration Makes Community Integration Work

Alison Mann Rinehart lives in a house in St. Paul, Minnesota, with three friends—Mindy, Damon and Tyler. They make their own breakfast, and with some help from a deaf woman who lives with the kids and is responsible for their overnight care, Ali and Mindy take the public school bus to Humboldt High School. Tyler gets ready for Metro Mobility to transport him to and from work in nearby Roseville. Damon heads out to work in St. Paul.

Just finding school programs and jobs (not to mention housing and care) for four deaf youth who have mental retardation and other disabilities took the collaboration of many agencies and scores of people.

Reginald Redding, then Assistant Superintendent for Curriculum and Instruction, MSAD, and Alison's parents, Peggy Mann and Gerald D. Rinehart, convened a meeting with representatives from numerous agencies, including the:

- State Department of Education;
- St. Paul School District;
- Minnesota State Academy for the Deaf (MSAD);
- State Department of Human Services (including the Deaf and Hard-of-Hearing and Developmental Disabilities Divisions);
- Division of Rehabilitation Services, Ramsey County Human Services; and
- Institute on Community Integration (the University of Minnesota's UAP).

They met for the first time just two years ago. "Unfortunately, there are no long-term programs in this state that serve deaf young adults with mental retardation. [We] wish to form a coalition in order to improve service options. Our goal for this first meeting will be to determine if there is a need and to identify various strategies to develop an independent living program for deaf or hard-of-hearing young adults with mental retardation," Redding wrote to the participants.

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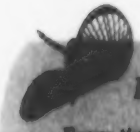

Editor's Note:

From time to time, the National Center for Youth with Disabilities highlights innovative projects that enhance the ability of adolescents and young adults to grow, develop, work and participate in community life to their fullest capacities. And while the story about the J.F. Best Group Home does that, it proved to be very difficult to write. You see, Alison is my daughter and this project is as emotionally charged as any milestone in our family; a college graduation, a marriage, the birth of a child.

We couldn't imagine Alison's future a mere 10 years ago. She was deaf. She had mental retardation. Some days she could walk without help, other days she needed to use a wheelchair. And some days she could barely stay awake. There were times when her hand or arm or mouth twitched uncontrollably, sometimes for days on end. She required multiple medications daily to be in precarious balance to protect her from seizures. She was fragile. A virus could keep her home from school for a week or compromise her enough to require hospitalization. She had no understanding of danger. It's awfully hard to imagine a future when all your energy is used to manage a child's problems and disabilities.

Alison's future began to take shape when we started asking the same questions we ask about all our children. What will she do? Where will she live? How will she find a meaningful place in her community? Who will be her friends? Where will she go to church? Where will she hang out? Alison's future began to take shape as we began to trust others to help us.

When a neighbor's home became a group home, I thought maybe Ali could just grow up and live nearby. Slowly, I could imagine a time when I would do what every other mom does with grown children. Take my daughter to lunch. Shop. I could imagine Ali visiting on birthdays and holidays, or stopping by on a Sunday afternoon, unannounced. I could imagine running into my daughter in the store or at the Y.

What we as a family and NCYD as a program have learned is that it is critical for families and youth to think about the future. The dreams we have for our children, and the dreams they have for themselves, will change and grow over time. And, kids and parents won't always agree.

These days, when Alison comes to her our house, she's delighted to eat my cooking, happy to see her younger brother, and she always asks about her older sister. But after a couple of hours, Alison will put on her coat and announce, "My house now." At 19, Alison still has all the same disabilities she had 10 years ago.

PMR

Collaboration
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While a number of the agencies involved had identified a need to increase the availability of communication accessible services for these youth, not much had moved ahead. A number of agencies even had interagency agreements in place, but they needed a catalyst, someone with a vision. "That's what the Rineharts provided. Having parents advocate for programming added immediacy to goals and objectives written by the Deaf Services (DSD) and Developmental Disabilities Divisions of the Minnesota Department of Human Services," JoLynn Blaesar, Planner, DSD, says.

This ad hoc coalition spent a year discussing how they might design, develop, fund, and evaluate a pilot transition program for up to 12 deaf youth that bridges all the agencies. The biggest difficulty? Identifying a site. Time and time again the team realized that youth with disabilities—especially in the area of communication—need to develop community living, job, recreation and independent living skills right in the communities where they will live. It just didn't make much sense to develop resources in one community when the youth would eventually move to another.

This notion might have stymied the work of the coalition if they had limited their understanding of community to geography. But at the same time, a deaf service provider was knocking at the county's door, wanting to provide group home services for deaf youth. Steven Hogenmiller and his wife, Monica, had both worked in group homes, sometimes with deaf people. They saw the frustration that limited communication added to their clients lives. Their goal was to start a service provision company, Laurant Clerc Services, Inc., to provide skilled care and programming in American Sign Language for deaf youth with developmental disabilities." Our goal is to create an environment for language development, communication and socialization improvement using community resources to build self-esteem and confidence," Hogenmiller explained.

DHS & County Social Services Combined Strengths

From that point on, natural work groups developed. County social workers made application for special waivers. Thirteen months after the first meeting, four youth from three counties who had

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attended the Minnesota State Academy for the Deaf were offered the opportunity to move to St. Paul, Minnesota, and receive their services as part of the Deaf community.

State and county human services developed a strategy to assist the Hogenmillers to become county providers of adult foster care. The mountain of reports, license application and paperwork involved in becoming county approved providers is daunting enough when English is your primary language. The county had never worked with a deaf provider before. But with technical assistance from both the Developmental Disability Services Division in the county and Deaf Services Division of State Human Services and the Hogenmillers' dogged persistence, the paperwork was completed by October 1—the day the home opened.

Contact:

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420 Delaware St. S.E.
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1242 Eustis St.
St. Paul, MN 55108

Creativity Stretches School Programs

In Minnesota, as in most states, children with dual disabilities have a tough time fitting into school. When Alison was placed with just deaf kids, she could understand the language but she couldn't manage the curriculum. When placed with peers who have mental retardation, she might be able to manage the curriculum, she just couldn't communicate with anyone. St. Paul school administrators and teachers struggled to make their strong community-based, independent living programming accessible to deaf children without breaking the bank. Part of the solution was to hire deaf adults and interpreters as job coaches and educational assistants. A greater part of the solution has been deliberately enhancing communication between programs and among program administrators.

Indeed, while interagency policy level administrators and planners were steering this sometimes unwieldy project, a second team of teachers and social workers, school nurses, aides, and *especially* Alison and her friends, were developing their own plan. Mo Fahnestock led the group in planning a meaningful and fulfilling life.

Still Growing

Collaborative projects built on mutual strengths take on a life of their own. They keep growing in depth and meaning as the community nurtures them. Alison, Mindy and Damon transferred to Humboldt High School in October; Damon is already working full-time in the community like his housemate, Tyler. Alison and Mindy will move to community sites this summer.

The Hogenmillers' company is thriving. They've provided employment for many skilled deaf people, and slowly these four youth are becoming members of the deaf community.

Nothing worth doing goes ahead without problems. Ali made an unnecessary emergency trip to the hospital one weekend. Mindy fell in school and chipped a tooth. The dishwasher needed to be replaced; the water heater wasn't big enough. And, Damon really did need a television of his own. Phyllis, the first "live-in" staff, was promoted, moved out, and El moved in.

But through it all, the kids are persevering, growing and, most important, learning how to become independent and finding their place in the neighborhood and in the community.

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Getting Youth Serving Agencies Together:

Where Do We Go From Here?

The publication, ***Together We Can: A Guide for Crafting a Pro Family System of Education and Human Services***, outlines a five-stage process for building a new system. While this publication looks to the really big picture, "to create a pro family system of integrated services to address the complicated problems children and families face in today's society," the stages identified can provide a road map for families and youth as they plan their futures.

Stage 1: Gather the right people and commit to collaborate. Communicate.

Stage 2: Identify a shared vision and goals that you can talk about in concrete language. Communicate.

Stage 3: Develop a strategic plan that defines exactly what you want to accomplish, who will do it and how. Communicate.

Stage 4: Take action. Communicate.

Stage 5: Adapt and expand the original plan as necessary. Communicate.

For More Information:

Connect With The National Resource Library

The National Resource Library brings together comprehensive sources of information related to adolescents, disability and transition to meet the needs of professionals who work with youth with disabilities as well as their parents and others invested in their success. The database contains five files:

- Bibliography
- Programs
- Training Materials
- Technical Assistance
- Health Care Reform

Entry points to the Library's files are through the language and issues of individual fields. Information in the files is interdisciplinary, offering the many views that may enhance practice with adolescents and young adults with disabilities.

The National Center for Youth with Disabilities is a program of the Society for Adolescent Medicine and the Adolescent Health Programs at the University of Minnesota. Publication of *Connections* is supported, in part, by project MCJ-275045 from the Maternal & Child Health program (Title V, Social Security Act), Health Resources & Services Administration, Department of Health & Human Services.

The Center's mission is to improve the health and social functioning of youth with disabilities through providing technical assistance and consultation, disseminating information, and increasing the coordination of services between the health care system and others. Center activities are directed at enabling youth to become full participants in their communities.

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HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Self-Funded Insurance Plans

Q My three-year-old son has autism. Our health insurance coverage is with a self-funded plan that is refusing to cover his medical expenses related to his autism. The plan does not cover treatment of "mental-nervous disorders," and this is how they have classified autism.

I have filed an appeal, pointing out that autism is a developmental disorder, not a psychiatric condition. Several of my son's doctors have written letters of support also. However, the appeal has been denied. Do you have any suggestions?

L.O., New York

A A variety of health insurance programs are available in the United States. There are traditional plans, managed-care plans, government-sponsored programs (including Medicare, Medicaid and a variety of state plans), self-funded plans and other, unique programs.

Each represents a different approach to health insurance, and each is regulated somewhat differently. Traditional health insurance plans, for instance, usually involve an agreement between an insurance company and an individual consumer. That agreement deals with issues such as the specific benefits that will be offered.

Traditional plans are usually regulated by the state in which the policy was issued. Government-sponsored plans are regulated by a specific state or federal agency, with benefits established by law and government regulation.

Self-funded plans

Although many people are more familiar with traditional health insurance plans, self-funded plans play an important role in the health insurance structure. In fact, more than 60 percent of Americans who have health insurance coverage through their employers are covered under self-funded plans.

Self-funded plans are typically established through an employer or union—the "plan sponsor"—rather than through an insurance company or government agency. The plan sponsor usually pays claims directly. Although an insurance company may be involved, it acts as a "third-party administrator," not as the insurer.

Therefore, in a self-funded plan, the insurance relationship is usually between an employee and his or her employer, not between a consumer and an insurance company or between a consumer and a government agency. Most self-funded plans are regulated under a federal law called ERISA—the Employee Retirement Income Security Act—not under state law.

The importance of regulation

The question of how a health insurance plan is regulated can be extremely important. Over the past few years, there have been a number of cases dealing with the ways self-funded plans have either limited benefits or class-ified medical conditions. Those cases have involved such conditions as Alzheimer's disease, cancer and AIDS.

Of course, all types of health insurance programs may exclude or limit coverage for specific services. Over the past few years, however, several states have issued new regulations mandating standardized health insurance plans that include a number of important consumer protections. But those regulations usually do not apply to self-funded plans.

The next step

Regardless of the type of insurance plan involved, the first step in a situation like yours is to go through appropriate appeal procedures. You've already completed that step, apparently without success.

Often, the second step would involve an appeal to your state insurance department. However, since your case involves a self-funded plan regulated under ERISA, the state insurance department probably cannot help.

However, there may be a number of legal issues involved in this case, including your rights under ERISA and under the Americans With Disabilities Act (ADA). Thus, I think your next step may be to consult an attorney who specializes in insurance or disability law. In your area, the Disability Law Center (c/o New York Lawyers for the Public Interest, 30 W. 21 St., 9th Fl., New York, NY 10010; 212/727-2270, voice; 212/727-2307, TTY) has an interest in helping people with such issues. *[EDITOR'S NOTE: In other areas, contact the National Legal Aid and Defense Association (1625 K St., NW, Ste. 800, Washington, DC 20006; 202/452-0620, voice; 202/872-1031, fax) for referrals to local resources.]*

You should also consider writing to federal legislators about this issue. Congress is beginning to discuss health insurance again. One topic that is likely to come up is the possibility of changing the ERISA law to bring self-funded health insurance plans under at least partial state regulation. Your experiences may help legislators better understand the situation as it relates to children with disabilities.

However, remember that companies are not obligated to offer health insurance coverage. Self-funded plans cost significantly less than traditional plans; according to the Self-Insurance Institute of America, many companies might not be able to offer *any* health insurance coverage if self-funded plans were not available. **EP**

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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ASK THE DOCTOR

by David Hirsch, M.D.

The Ketogenic Diet

Q Our four-year-old son has developmental delays and a very severe form of epilepsy. His seizures have been diagnosed as being myoclonic in form (rapid jerks of flexor muscles). Sometimes he seems to have staring spells which are seizures also. He has been on many different anticonvulsants—up to three at a time—but with minimal improvement in his seizures. My husband and I feel that the medications are making him very lethargic; he sleeps most of the day. We are strongly considering trying the "ketogenic diet" that we have heard about recently. Does this seem reasonable?

A A ketogenic diet for the control of seizures is a treatment for epilepsy that has been in use for many years—alone, or sometimes in conjunction with anticonvulsive medications (medications to control seizures). Although there are a few theories, nobody really knows why the diet reduces or stops seizures in certain children.

The ketogenic diet consists of foods that cause the body to produce ketones, primarily a byproduct of fat metabolism. A person on a well-balanced diet consisting of carbohydrates, protein and fats will derive energy primarily from the metabolism of glucose—metabolism being the process whereby food is converted to energy. In contrast, a person on a ketogenic diet derives energy from "burning" fat, rather than glucose.

A ketogenic diet consists of foods such as heavy cream, butter, other fats and only a limited amount of protein. Essentially no carbohydrates (sugar and starch) are allowed. Protein and calorie intake must be set at levels that meet requirements for growth. Vitamin supplements must also be used appropriately.

The ketogenic diet may sound much easier to do than it really is. It should *never* be attempted without very close medical and dietary supervision. Typically, the diet is started in a hospital setting after several days of severe caloric restriction. This initial restriction of food intake causes the body to begin "burning" fat for energy, starting the production of ketones. During this initial hospitalization, a dietitian works with the family and child to set guidelines for the types and amounts of food the child may have. Once started, and barring any major complications, it is essential that the patient follow the diet strictly. "Cheating"—whether accidental or intentional—may result in increasing or restarting seizures.

According to studies done at Johns Hopkins Pediatric Epilepsy Center, the optimal age for the diet is between one and eight years. Younger children are more prone to hypoglycemia (low blood sugar) when on the diet and older children who are oral feeders (as opposed to tube feeders) are more resistant to following the ketogenic diet, primarily because of its limited taste appeal.

The ketogenic diet should be considered another therapeutic option, just as the option to use or change anticonvulsant medications. This diet should not be the first choice among options for seizure control, but it is a viable treatment for children with many types of seizures that are not well controlled with anticonvulsants or where anticonvulsants cause significant side effects.

Just as with drugs, the ketogenic diet has potential side effects including hunger, thirst (because of the decrease in fluids taken in as part of the diet), constipation (because of the small volume of food and high concentration of fat in the diet), hypoglycemia, kidney stones (because of too little liquid), hypocalcemia (low blood calcium), hyperuricemia (excessive uric acid in the blood) and acidosis (a build-up of acid in the blood). Also, if a child continues taking anticonvulsant medication, the ketogenic diet may make him more prone to a buildup of the medication in the body because the diet may change the way the body absorbs the medication, the way medication adheres to proteins in the body or the way the brain metabolizes the medication. As mentioned above, the diet must be rigorously adhered to and closely monitored. Even slight amounts of excess carbohydrate may precipitate a seizure in susceptible individuals.

Johns Hopkins has reported that the ketogenic diet appears to be very effective and typically well-accepted by patients and families. Of children with the most intractable epilepsy (the hardest to control), Johns Hopkins reports improved seizure control in 67 percent. Many of these children were able to reduce their anticonvulsant medications significantly; some were able to stop the medications entirely. Speaking from personal experience, I have had

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In this column, David Hirsch, M.D., a pediatrician and member of the EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch mentions specific products or medications only to illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-8742 (Fax).

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Circle #11

Age Appropriate Beds

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HARD Manufacturing Co Inc

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Circle #44

ASK THE DOCTOR

continued from page 56

two patients recently who have had significant improvement in seizure control and quality of life on the ketogenic diet. One is no longer on antiepileptic medications.

I believe there may be a role for the ketogenic diet for your son. Again, the ketogenic diet—like the use of any medication—is a serious undertaking and must be done under the close supervision of your son's pediatrician and pediatric neurologist and by a dietitian who is experienced with the diet.

For more information, you may want to investigate the following resources:

- *The Epilepsy Diet Treatment: An Introduction to the Ketogenic Diet* (paperback, 1994, 180 pp.): Written by medical professionals at Johns Hopkins; Demos Publications, 386 Park Ave. S., Ste. 201, New York, NY 10016; (800) 532-8663; $21.95.
- *An Introduction to the Ketogenic Diet: A Treatment for Pediatric Epilepsy* (video, 45 min.): The Charlie Foundation, 1223 Wilshire Blvd., Box 815, Santa Monica, CA 90403; free (send card with name and address).
- *The Johns Hopkins Ketogenic Diet Fact Sheet* (fact-sheet, 4 pp.): The Epilepsy Foundation of America, 4351 Garden City Dr., Landover, MD 20785-2267, (800) 332-1000; free. **EP**

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DIESTCO Mfg. Co., P.O. Box 6504, Chico, CA 95927

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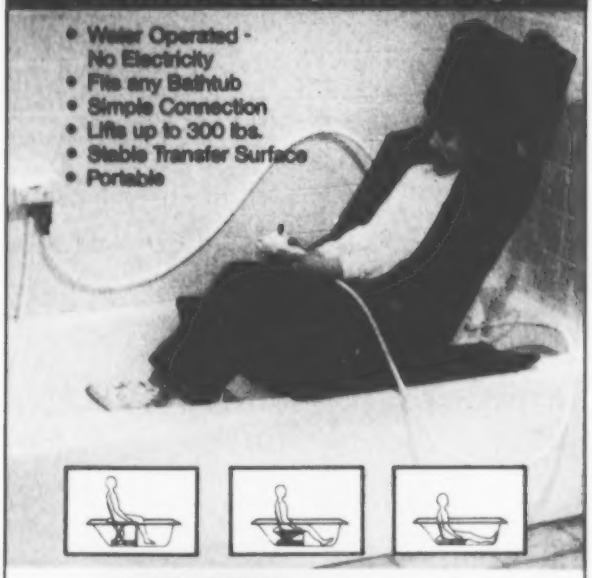

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Oakdale, PA 15071-9223
Phone: (412) 695-2122 • Fax: (412) 695-2922

Circle #180

Free Product & Service Information

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This Reply Card enables you to receive FREE information about products and services seen in *Exceptional Parent*.

How to use this service:

1. Locate the number at the bottom of each ad or refer to the Directory of Advertisers.
2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the *postage-paid* card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly. Be sure to tell them you saw their ad in *Exceptional Parent*!

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(800) 247-8080 New subscriptions only
(800) 562-1973 Customer Service, U.S. only. For international customer service, call 201-627-4671

Exceptional Parent magazine has accepted product and service advertising since 1973 because advertising provides important information for consumers. The acceptance of advertising in *Exceptional Parent* does not constitute nor imply endorsement by *Exceptional Parent* magazine, its editors or its Editorial Advisory Board. Readers need to consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

EDITORIAL INFORMATION: Contact Dr. Stanley Klein, *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

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MICROFILM: Microfilms of all issues are available from University Microfilms, 300 North Zeeb Road, Ann Arbor, MI 48106.

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EXCEPTIONAL PARENT

July 1995

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☐ Yes ☐ No (If no, please see the subscription card in this issue.)

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Facility _____

Address _____

_____

City _____ State _____ Zip _____

Phone _____ Fax _____

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? ☐ Yes ☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ☐ Yes ☐ No

If Yes, are you a: ☐ Physician ☐ RN ☐ Physical Therapist ☐ Occupational Therapist ☐ Speech Pathologist, Audiologist ☐ Other (please indicate) _____

D. Are you an EDUCATOR? ☐ Yes ☐ No

If Yes, are you a: ☐ Special Ed Teacher ☐ Regular Ed Teacher ☐ Admin/Dir ☐ Other (please indicate) _____

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? ☐ Yes ☐ No

If yes, please explain _____

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If yes, please explain _____

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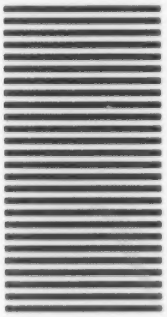

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NEW PRODUCTS

BLOCKS IN MOTION

Unlike traditional computer paint programs, which require fine motor skills to perform a series of complex steps, Blocks in Motion allows a child to select a shape from a palette of shapes, click on it, point the mouse to the position on the background where the shape is to be placed, and click again to drop the shape into place. By joining a series of shapes similar to building blocks, children can create whole pictures. Requires a Macintosh computer with System 7.0 or higher, color monitor, three megabytes hard drive space, two megabytes RAM and a mouse.

Don Johnston, Inc., Wauconda, IL 60084-0639

Circle # 195

ACTION VOICE

This portable communication device allows children to communicate using pre-recorded messages. The one-minute model allows 10 messages to be recorded. The two-minute model features an 18-message recording capacity, enhanced volume and auditory scanning. Both models allow two adapted appliances, toys or other devices to be controlled by any of the recorded messages. The Action Voice supports scanning, switch input or keypad overlays.

Ability Research, Inc., Minnetonka, MN 55345-0121

Circle # 196

THE ARROW WALKER

The Arrow Walker is an adjustable walker designed to provide children with hands-free independent mobility in an upright position. This walker features an arrow-shaped chassis for stability and easier access through doorways and around obstacles. Directional locking casters allow the user to walk a planned course. A choice of three sizes (tiny, small and medium) and positioning accessories allow for customization.

Triaid, Inc., Cumberland, MD 21502

Circle # 197

VOCAL ASSISTANT

This augmentative communication device allows 16 messages to be recorded in any voice and in any language. All messages are available for playback at the touch of a single key. The first six messages may be of extended length, allowing addresses, phone numbers and complex sentences to be recorded. Optional accessories include a remote speaker, keyguard and telephone interface.

GMR Labs, Sunnyvale, CA 94087

Circle # 198

THE ADJUSTABLE

This height-adjustable table can be adjusted from a height of 25 to 50 inches with a minimum of effort. The adjusting mechanism consists of two cylinders controlled by hand levers on either side of the table. The levers are depressed to adjust the table, and released to lock it into position. A single-lever, one-handed adjustment lever is available. Additional cylinders may be added to reduce the amount of effort required to adjust the table with heavier loads. An adjustable-angle table top with settings from 5 to 40 degrees is also available.

Northport, Inc., Excelsior, MN 55331

Circle # 199

PURE FLITE GEAR BAGS

Pure Flite Gear Bags are gear bags designed for active kids and teenagers with physical disabilities. The design of the bags allows access to belongings without having to set aside crutches or reach around to the rear of a wheelchair. The student model, worn over the shoulders against the chest, features a large zippered top pocket to carry legal-size notebooks, books and folders. A smaller easy-access pocket holds keys and wallets.

Pure Flite Gear, Pompano Beach, FL 33064

Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

WHAT'S HAPPENING

Video and Monograph Focus on the Power of Friendship

The Texas Planning Council for Developmental Disabilities has produced a 16-minute, open-captioned video, *Just Friends,* and a 42-page collection of stories, *Community Connections: Weaving Friendships.* Both highlight the experiences of teenagers and adults who participated in the Council's "Community Connections" projects. The projects, developed in seven areas across the state and intended to promote community inclusion, matched individuals with and without disabilities.

For a free copy of the video and/or monograph, contact Nancy Arms, Texas Planning Council for Developmental Disabilities, 4900 North Lamar Blvd., Austin, TX 78751-2399; (512) 483-4080 or (800) 262-0334 (TX only). A limited quantity is available; one copy of video and monograph per person or organization.

One of the 15 stories in *Community Connections* focuses on the friendship between (from left) Brandy Pulliam, Amanda Iseli and Ginny Stander, all of Lubbock, Texas. Brandy has lived in a nursing home since the age of 13, when she lapsed into a three-month coma following a seizure. After regaining consciousness, she could no longer walk or talk. When asked how she and Amanda communicate with Brandy, Ginny replies, "Oh, that's no problem. Brandy talks with her eyes." And what's the main topic of conversation when this threesome gets together? "Oh... you know... guys."

Uncommon Fathers: Reflections on Raising a Child with a Disability is a collection of essays written by fathers of children with disabilities. These diverse dads have children ranging in age from four to 28, with a variety of disabilities. Fathers of children with disabilities will meet peers in the pages of this book. Mothers who read this book will gain insight into the perspectives of their children's fathers. And professionals will benefit from learning how the fathers represented in this book strive to be vital participants in their children's lives.

Uncommon Fathers, edited by Donald J. Meyer and published by Woodbine House, is available through Exceptional Parent Library, (800) 535-1910. 206 pp; $14.95 (paperback).

Young Musicians Competition

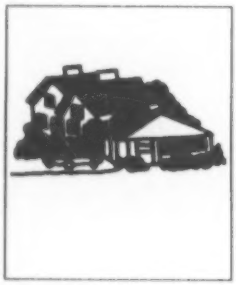
Very Special Arts, an international organization providing creative opportunities in the arts for children and young adults with disabilities, is accepting entries for the 1996 Panasonic Young Soloists Award. Any instrumentalist or vocalist with a disability, younger than 25 and interested in pursuing personal or professional studies in music may apply. Each entrant must submit a video or audio recording of their work, a letter of application and a 250-word autobiographical statement detailing why he or she should be selected for the award. A committee of music professionals and educators will award $5,000 scholarships to one or two winners. Each winner will also have the opportunity to perform at the John F. Kennedy Center for the Performing Arts in Washington, DC.

To receive an information packet, contact Very Special Arts, Young Soloists Program, Education Office, The John F. Kennedy Center for the Performing Arts, Washington, DC 20566; (800) 933-8721, voice; (202) 737-0645, TTY. The deadline for entries is September 15, 1995.

CHILDREN'S CARE HOSPITAL & SCHOOL
For Children with Disabilities and Their Families

CHILDREN'S CARE HOSPITAL & SCHOOL *(formerly Crippled Children's Hospital & School)* is a private, nonprofit facility serving over 1000 children and families each year. Individualized, family-centered programs available through day school, outpatient, outreach, or residence. Pediatric rehabilitation program now offered.

Contact: Nathan Anderson
Children's Care Hospital & School
2501 West 26th Street
Sioux Falls, SD 57105-2498
(605) 336-1840 or (800) 584-9294



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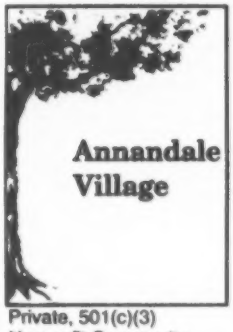
Contact: Admissions Director
The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000



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(404) 945-8381

C55

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81 Rumford Ave.
Waltham, MA 02254-9055
(617) 894-0069
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Missouri

U.S. Medical Corporation
14575 Manchester Road
Manchester, MO 63011
(800) 40-USMED/(800) 408-7633

Free Catalogs

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P.O. Box 684
Sheboygan, WI 53082-0684
(414) 459-8353

Incontinence

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Leipsic, OH 45856
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Call DMP for all your incontinent needs such as briefs, pants, pads and liners, as well as skin care products. Call for FREE catalog!

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1215 Dielman Industrial Court
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(800) 538-1036
See our ad in this issue.

Summers Laboratories, Inc.
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(800) 533-SKIN (7546)
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Manchester, MO 63011
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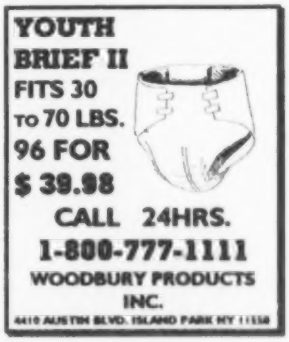
Call U.S. Med for free sample Depend briefs, undergarments, pants and diapers.
Low prices and free delivery



Monitoring Systems

A & H International Products,Inc.
301 E. Ocean Blvd., #1010
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(310) 435-1011
BeeperKid child monitor helps protect your child in public. Instantly alarms you before child can wander or get lost.

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FREE catalog!

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Los Angeles, CA 90024
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Van Conversion Dealers

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Drive-Master, Inc.
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Indiana

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214 Valley Street, Dayton, OH 45404
(513) 222-5001
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Kentucky

Forward Motions
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(513) 222-5001
Full-size/Mini-Van modifications, new/used lifts, drop floor, raised roof, lockdowns, driving equip. NMEDA member. Owned by person with disability.

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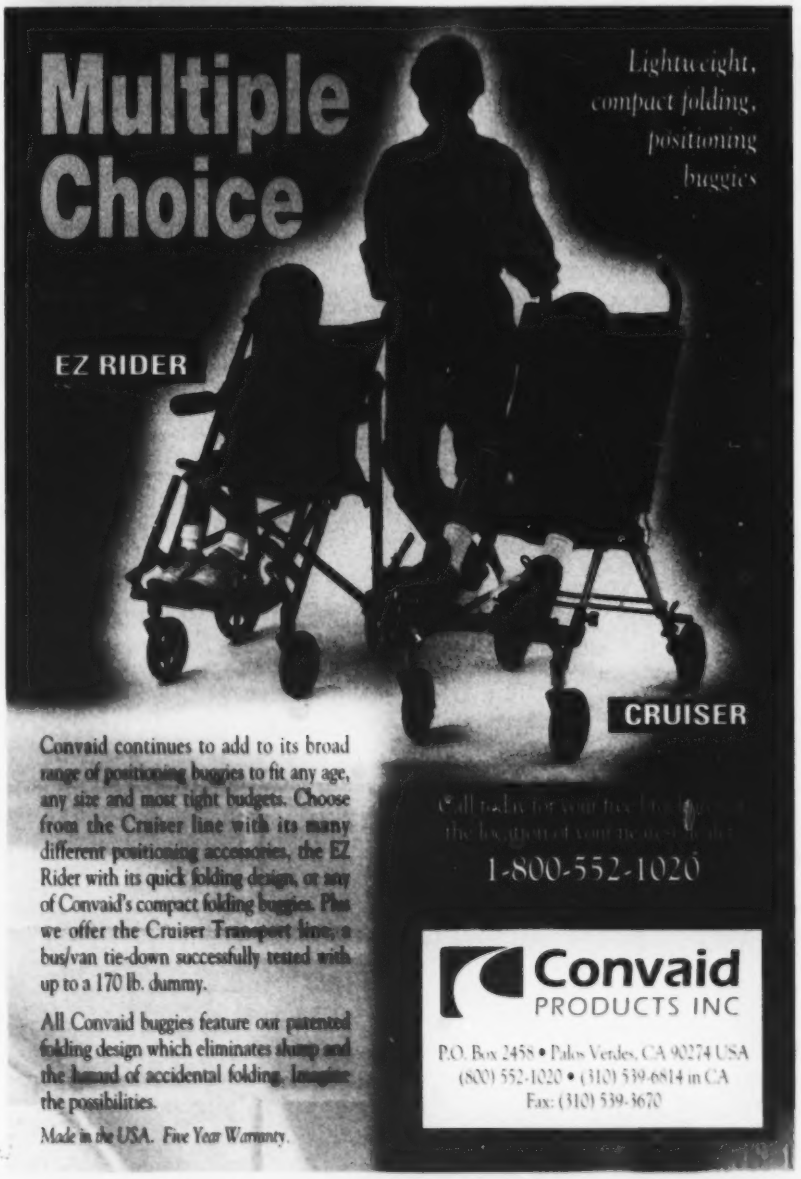
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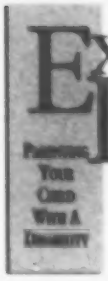

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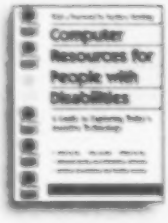

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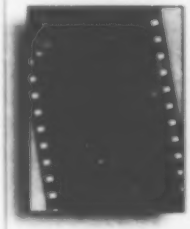

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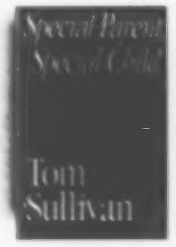

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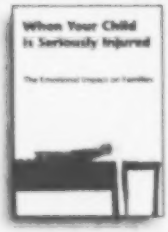

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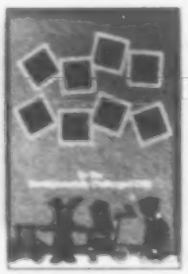

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FRIENDSHIP

CHILDREN'S PAGE

"BESTEST BUDDIES"

by Kristen Gain

By sitting on the back of the swing, Kristen has figured out a way to give both herself and Erin a wild ride at the same time.

Kristen Gain helps "bestest buddy" Erin Tatro smile for the camera.

My name is Kristen. I'm seven years old, and this is my story about my friend Erin Tatro.

Erin has cerebral palsy; her muscles don't work the same way as everybody else's. She kicks a lot and she moves her arms a lot. She giggles a lot, and she hums and grinds her teeth. She talks with a yes/no board with her hands and sometimes with her feet. She gets sick a lot, too.

I met Erin in kindergarten. At recess, I liked to push her in her chair.

Erin is in my first grade class, too. I like to help Erin if I finish my work early. I especially like to push her around on the field. She likes to be pushed on the bumpy part of the field. Sometimes, I get to ride Erin's bus home with her.

At Erin's house I like to swing, help Erin walk in her walker, do homework with her and sleep over. I like to ride in Erin's van and play her music tapes. On Saturday mornings, I like to go bowling with Erin and set up the bowling ramp so she can get strikes. We get good scores together. We're in Brownies together, too. And we like to go to the movies, like the *Lion King*.

Me and Erin are bestest buddies. Best of all, when I tell Erin secrets, she doesn't tell anybody. **EP**

Seven-year-olds Kristen and Erin know the best way to cool off on those hot California afternoons.

Kristen Gain, 7, will soon be a second-grader at Pines Elementary School in Magalia, California. She lives with her parents, Tony and Nancy, brother Ryan, 12, and sister Kaylin, 9. Her hobbies include drawing, skating and riding her bike.

Mom's Turn:

I like to bring Kristen along when I need to do some shopping. It's wonderful to have an extra pair of hands to push Erin's wheelchair. Kristen enjoys these trips, too; when she comes over, she'll often ask, "Do you need to go somewhere today?"

With my permission, Kristen and Erin especially like to roam the store without me. As I shop, they stroll the aisles looking at things that are more interesting to kids. They also like to hide from me. Out of the corner of my eye, I often notice Kristen hurriedly pushing Erin by the end of the aisle I'm in, hoping I don't notice them. But I usually know where they are because Erin often makes a humming sound or grinds her teeth. Etched in my mind forever is a picture of Kristen pushing Erin's wheelchair down an aisle with one hand, while the other hand was wrapped around Erin's face to cover her mouth; Erin's hum was particularly loud that day and was giving away their position.

—Donna Tatro

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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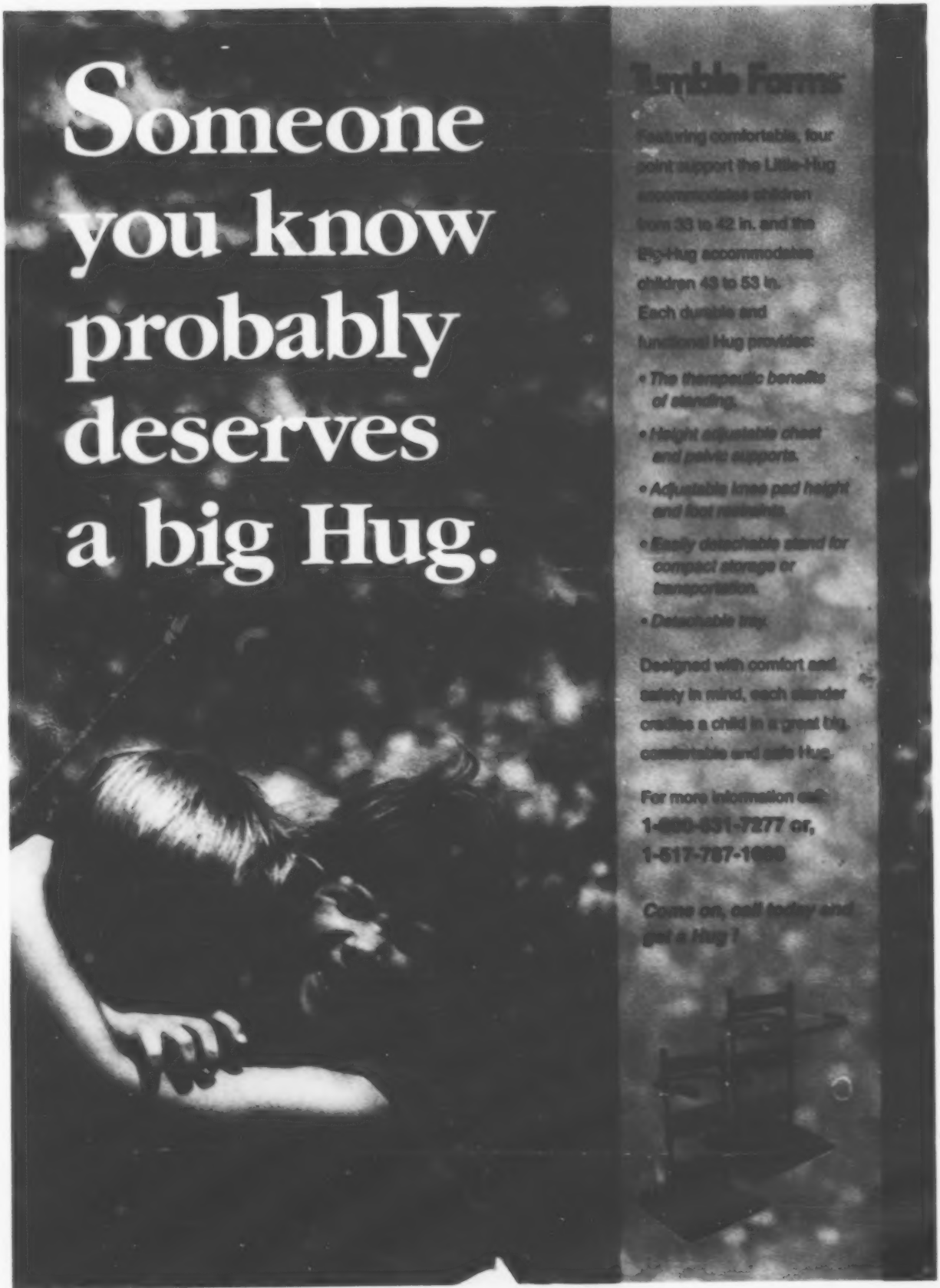
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EXCEPTIONAL PARENT

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AUGUST 1995 VOL. 25, ISSUE 8

PAGE 29

Cover: *Kelly Bankston, of The Orange Grove Center in Chattanooga, Tennessee, practices with Dr. Rick Rader for a presentation to medical students, interns and residents. Physicians-in-training typically have little exposure to people with disabilities. Dr. Rader's innovative Developmental Disabilities Patient Simulator program (see page 36) aims to change all that.*

Kelly, one of three "patient simulators" with developmental disabilities, "presents" a unique upper arm contracture and has learned to assist physicians in their approach and communication techniques. In Kelly's first outing, she suggested to a nervous intern that the doctor would get a better "feel" for the contracture by first removing her bulky ski jacket.

Kelly, 14, has cerebral palsy, hydrocephalus, seizure disorder, visual and hearing impairments, curvature of the spine and a keen sense of humor. Photo: Dennis Wilkes.

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EDITOR'S DESK

IDEA and ADA: Positive legislative changes

At the end of June, the U.S. Department of Education submitted its proposals to Congress to improve the Individuals with Disabilities Education Act (IDEA). These proposals (see page 57) were based on input from more than 3,000 parents and educators. This will be the first substantial revision of the law since 1975.

STANLEY D. KLEIN, PH.D.

In the last 20 years, this legislation has had a dramatic effect on the lives of millions of children and adults with disabilities and their families, as well as on all Americans. Today, our society is far more welcoming and inclusive. We urge our readers to urge their legislators to support the reauthorization of this important legislation.

This summer marks the fifth anniversary of another important piece of legislation—the Americans with Disabilities Act (ADA). In its short history, the ADA has also contributed to far greater community participation for people with disabilities of all ages.

Both IDEA and ADA were enacted because parents and people with disabilities worked tirelessly to inform members of Congress about their needs. Today, with all the talk in Washington about returning to old ways of doing things, we need to remind our elected officials that the results of these legislative changes have been positive for *all* citizens.

Health

All too often, parents' relationships with health care professionals are not the partnerships described by Irene Pollin in her wonderful book, *Taking Charge* (see page 53). Sometimes, parents and professionals become adversaries and "forget" their shared concerns about a child's well-being.

Gradual changes in the education of professionals have contributed to increasing collaboration between parents and professionals—especially when parents and individuals with disabilities have become directly involved in the professional education process. In this issue, we are delighted to report on an exciting new program in which children and young adults with disabilities are teaching physicians (see page 35). We hope this program, created by Dr. Rick Rader, will serve as an example. We are also pleased that Dr. Rader has joined our Editorial Advisory Board.

Recently, professionals have started talking more about the emotions of parents of children with disabilities. Still rarely, however, do professionals discuss their own feelings. We know that such discussions—difficult as they may be—will be stimulated by "This Doctor's Point of View," an unfinished essay by the late Dr. Arthur Weber.

Special Olympics

Thanks to our wonderful staff and friends, 75,000 copies of a special issue of EXCEPTIONAL PARENT were distributed at the 1995 Special Olympics World Summer Games. We enjoyed seeing the thousands of excited and proud athletes from all corners of the globe. A world in which the horrors of ethnic, cultural and class warfare occur all too frequently could learn much from these spirited, caring athletes who just happen to have intellectual limitations.

Subscription prices

Every few years, though cognizant of the financial burdens many readers face, I have the unwelcome task of announcing a subscription price increase. The costs of postage and paper have increased significantly. As a result, we must raise the price of a one-year subscription to $28, effective November 1, 1995. The good news is that all subscribers will have an opportunity to renew their subscriptions at the current price. While we know our magazine provides valuable information, we also know that costs of so many things seem unfair. We appreciate our readers' understanding and loyalty.

EXCEPTIONAL PARENT
The Magazine for Families and Professionals
Printing Your Concerns Topic About With A Disability

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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 58.

BPA

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ss Report

Outcomes: Posture, function, and [illegible] improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.

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LETTERS

An Invaluable Resource

I am an occupational therapist, and your magazine is an invaluable resource for me. I have shared it with parents, used it to locate organizations and products, and have learned much from the articles I've read in it. It is very interesting and enjoyable reading—I prefer it to my popular and professional publications.

S.S., Illinois

Cover to Cover

Like so many of your readers, I sit down and read the magazine from cover to cover, just as soon as I can—usually within hours of its arrival in our mailbox! I am often touched by the articles and letters from parents, especially *Search* letters from parents of children with rare conditions. I feel grateful to have a daughter with a relatively common disability—Down syndrome.

I've passed articles on to other people. I've laughed, I've cried and I've even been outraged on occasion. Thank you for a wonderful, informative and up-to-date magazine that really hits the spot with me.

J.T., California

Facilitated Communication

My daughter and I were sitting in Dr. David Hirsch's office two weeks ago when I picked up the May issue of EXCEPTIONAL PARENT. After looking at the cover, I told my daughter that there was another article on facilitated communication (FC). I said a prayer that maybe *this* magazine had published a fair, up-to-date article, based on the facts.

Not to our surprise, but much to our disappointment, you did nothing but continue to print misinformation. Those of us with children who benefit from FC have never claimed that FC will benefit every nonverbal person. We ask only for fairness.

Why didn't you print an article by Dr. Doug Biklen—one just as long and detailed as the Levine/Wharton article—side-by-side with the negative article? Why didn't you list the Syracuse University FC Institute as an information resource? Why doesn't EXCEPTIONAL PARENT allow parents to make their own judgments about what may or may not work for their children?

My daughter is blind and nonverbal. Her use of FC has been validated by a competent psychologist. FC has changed her life; she now uses FC with seven different individuals. What else does my daughter have to do to prove her competence?

J.U., Arizona

■ I was appalled that the May issue of EXCEPTIONAL PARENT declared FC "not a valid approach to communication." Your coverage of FC was very unbalanced and clearly communicated a decision to "trash" FC. I understood that Dr. Biklen would present another point of view in another issue, but his article should have appeared in May. Your lead article on FC, the first ever by EXCEPTIONAL

continued on page 6

EXCEPTIONAL PARENT

To reach out to parents of children and young adults with disabilities and special health care needs and to the professionals who serve families

To empower parents and professionals by providing practical information and emotional support.

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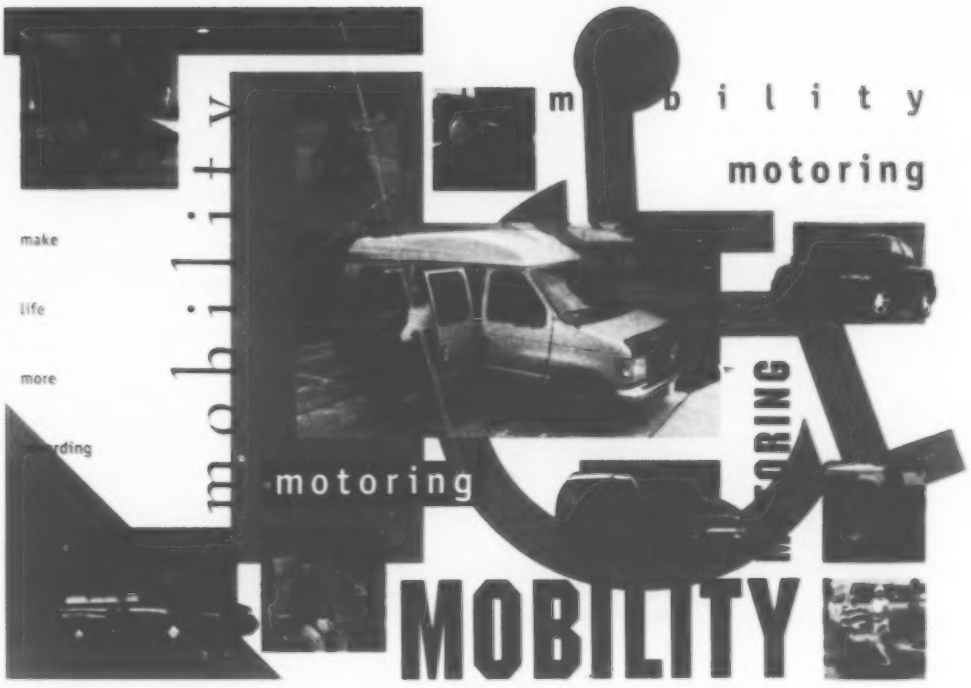

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Circle #3

LETTERS

continued from page 4

PARENT, seriously misrepresented this valuable communication method. I believe you have done untold harm for the future of FC, because there are parents who take the information presented in EXCEPTIONAL PARENT as "gospel." This article has the force to stop many parents and educators from pursuing the truth.

I've worked in the parent business for 21 years. I've talked to parents from all over the country. I've met and observed their children. I've listened to their tribulations and triumphs. I have been privileged to hear the reports of many FC successes, many FC disappointments and some FC failures. I'm sorry you haven't seen and heard the same things. I believe you've made a substantial error.

You neglected to speak to a number of experts before running this article. In fact, Rosemary Crossley was in the States at that time. Did you interview her? Did you talk to 1981 Nobel Prize laureate (physics) Dr. Arthur Schawlow, who has testified to the effectiveness of FC? Did you watch the video clips of Sharisa Kochmeister, who learned to communicate through FC and now types without any physical support?

By now, you know I'm upset and disappointed with EXCEPTIONAL PARENT. The most disturbing aspect of this controversy is that you have joined with certain "professionals," in opposition to parents. And just so you don't misunderstand, I have

Tell us about...

... your child's relationship with grandparents and other relatives.

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.

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enormous empathy for parents like those who told the story about being falsely accused of abuse through FC ("An FC Nightmare"). Yes, there have been mistakes and abuses—plenty of them; most have been perpetrated by professionals. I work to stop these kinds of abuses.

For many years, EXCEPTIONAL PARENT has worked to empower parents. But in this case, *you* decided—not the parents. I believe you will learn that you were wrong. Next time, please call the real experts!

Patricia McGill Smith, Executive Director
National Parent Network on Disabilities (NPND)
Washington, DC

■ I was horrified when I read the article about FC in your May issue. Four years ago, I started babysitting for a beautiful three-year-old girl who had been born with a chromosomal disorder. She used sign language and knew about 100 signs.

Two years ago, a therapist introduced her to FC. Testing showed she had the vocabulary of a eight-year-old, but couldn't verbalize the words she knew. I was not surprised. I had always treated her like any other child the same age, but FC made my job a lot easier.

Not just anyone can facilitate. A facilitator must have faith in the child. He or she must also know how to hold a child's hand properly; pulling back on the child's hand not only prevents facilitator influence, it also gives the child stability and confidence.

The frightened three-year-old I met four years ago is now a first grader in a public school. She is in a regular classroom and can speak clearly using three- and four-word phrases. She points to what she wants without any physical guidance. She is confident in her own abilities; often, when I try to help her, she says, "By myself. Go away."

As for allegations of child abuse, it is imperative that we assume that children do not lie. My heart goes out to anyone who is wrongly accused of child abuse, but I would rather see someone falsely accused of abuse than see a guilty person not be accused. The story by the facilitator who "wrongly" accused a family of abuse disturbed me ("From Someone Who's Been There and Back"). The law requires school officials to report suspicion of child abuse within hours, not weeks. I wonder why it took weeks of facilitating by a number of people to report the suspected abuse, but only one day to label FC as evil.

B.T., Connecticut

"Warm Fuzzy"

I'm a new subscriber, but wish I'd known about you a long time ago. I've already gotten so much good out of your magazine. Keep up the excellent work—this magazine is a real "warm fuzzy" in a very busy, hectic and hard world.

A.S., Illinois

continued on page 8

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Circle #98

continued from page 7

Straight From The Heart

Like many people who write to you, I have a child with a disability. I used to feel like I was the only one with a child who has so many needs. I constantly prayed for all the problems to go away and for my life to be normal. I cried so much and was sad all the time.

My two-year-old son has cerebral palsy. He tries to talk and pull himself up, but he knows he can't. But he is always happy, laughing and playing. Whenever I'm upset or sad, he makes me smile. He always shows me how much he loves me.

I am 16 years old. I had to grow up real fast after my son was born, but if I had the chance to replace him with a "normal" child, I wouldn't do it for the world. I now realize how lucky I am to have him. Children with special needs can teach you a lot about life.

I want to say how wonderful EXCEPTIONAL PARENT is; I've never read any other magazine that makes me feel so good. All the stories are written by real people talking about their real experiences and feelings. It's straight from the heart.

C.B., California

Hearing Impairment and Hearing Aids

I am writing in response to "Hearing Impairment and Hearing Aids" (May 1995). I am the mother of two children with bilateral hearing impairments, and although I agree with most points in the article, I disagree with the author's recommendation that a child's hearing aids be checked every three months. This could get quite expensive because most insurance companies do not cover any expenses related to the aids. These are out-of-pocket expenses.

With training from the audiologist on the use of the dri-aid kit, stethoscope and battery tester, most parents should be able to avoid problems or catch them if they occur. I have my children's aids checked yearly, or any other time a problem arises.

I'd also like to add a suggestion for other parents: it is a good idea to include on your child's IEP that he or she be seated at the front of the class. This will allow the child to maximize the benefits of his or her hearing aids with less auditory interference.

S.P., Iowa

Fragile X Syndrome

Thank you very much for the *two* articles featuring fragile X syndrome that appeared in the June 1995 issue. I have been reading EXCEPTIONAL PARENT since my son was diagnosed with fragile X in 1991 and have seen this condition mentioned only rarely. I am a strong advocate for letting others know about this very common cause of developmental disabilities.

K.M., Virginia

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C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? ☐ Yes ☐ No

If Yes, are you a: ☐ Physician ☐ RN ☐ Physical Therapist ☐ Occupational Therapist ☐ Speech Pathologist, Audiologist ☐ Other (please indicate) _____

D. Are you an EDUCATOR? ☐ Yes ☐ No

If Yes, are you a: ☐ Special Ed Teacher ☐ Regular Ed Teacher ☐ Admin/Dir. ☐ Other (please indicate) _____

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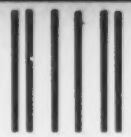

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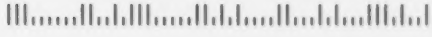

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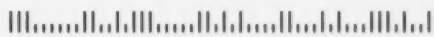

SEARCH

Supervising a "Runner"

My three-year-old son has autism. He is considered a "runner." If not constantly supervised, he will run away. If a door is left ajar, he can open it. Once outside, he'll run and run! It's very frightening. We have notified the local police department because Jimmy cannot talk, and if he ever got away from us, we wouldn't know how to track him down. We tried a "tracking device" attached to his clothing, but he would not keep it on.

I constantly fear for his safety. In south Florida, where we live, there is water everywhere! We keep the house locked up like Fort Knox and try to watch him at all times, but we're still afraid he might get away from us. Are there any other parents out there with a child who is a "runner?" Please help!

L.K., Florida

Two Undiagnosed Children

We are the proud parents of three lovely daughters, two of whom have disabilities. Our oldest daughter is from a previous relationship and is perfectly healthy. Our second child, Brittany, 3, was born with congenital heart defects (atrial and ventricular septal defects) and a neural tube defect which resulted in the tethering of her spinal cord (spina bifida occulta). Accompanying these defects are global developmental delays and farsightedness.

After Brittany underwent heart surgery, she developed reflux and tactile defensiveness, resulting in a refusal to eat, which caused failure to thrive. Brittany was evaluated by several geneticists. Although they mentioned that she had dysmorphic facial features, they assured us Brittany did not have a syndrome; the results of chromosome studies were normal. These specialists did not believe we had any risk of having another child with the same disabilities.

After careful consideration, we decided to have another child. The pregnancy was closely monitored. No problems were detected until the seventh month, when doctors found a problem with the placenta and recommended early delivery due to fetal distress. When our child was born, doctors discovered she had the same congenital heart problems and neural tube defects as her older sister. She also has dysmorphic features and global developmental delays. Again, chromosome studies appeared normal.

To this day, we have no diagnosis for our two youngest daughters; doctors are completely mystified. We would like to hear from anyone who knows of children with the same problems or characteristics.

M.M. & J.M., Ontario, Canada

Unprepared

My son, Ian, was born 13 weeks premature and weighed only one and a half pounds. He had a grade I brain bleed and periventricular leukomalacia, a condition in which tissue around the brain's ventricles (chambers in which cerebrospinal fluid is made and circulated) is damaged due to insufficient blood flow or lack of oxygen.

We brought Ian home knowing things wouldn't be perfect, but we didn't realize how difficult it would be. He has recently been diagnosed with spastic quadriplegic cerebral palsy. At 21 months of age, he cannot sit, roll from back to front or crawl. He babbles but does not say any words. He has had two fundoplications with g-tube placement, and three bilateral inguinal hernias. He is scheduled for another operation to correct strabismus. He does not eat and the doctors still have not determined if this is due to a swallowing dysfunction. Doctors cannot yet make any determinations about Ian's mental and physical status.

Our family needs a nurse to come along with us when we do anything together. It is hard for us to imagine a whole life of planning every minute. What do other parents do if they want to take their child to a restaurant, to the park, to the mall? Because my husband and I both work, our income prevents Ian from getting any financial assistance. I wanted to get a tray accessory for Ian's new chair, but it costs $400 and although the insurance paid for the chair, they will not pay for any accessories. How do parents obtain these items without going broke?

I would like to hear from parents with children who have any of the same conditions as my son. Any suggestions and all letters will be greatly appreciated.

J.B., New Jersey

Turner Syndrome, Opitz Syndrome, G-Tube Problems

Our youngest daughter, three-year-old Haley, has Turner syndrome (a chromosomal disorder affecting only females, caused by the lack of one of the X chromosomes in all or some of the body's cells) and Opitz syndrome (a rare hereditary disorder characterized by wide-set eyes, cleft lip and/or palate and swallowing problems). Haley has a double chromosomal cell line of 45XO, which is Turner syndrome, and

continued on page 12

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (V/TTY).

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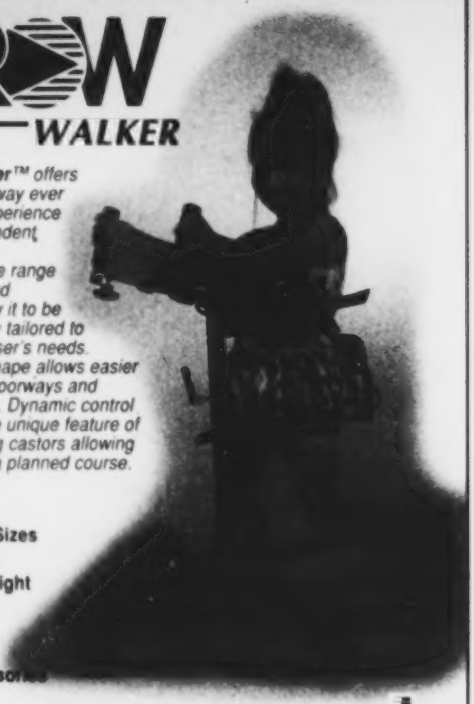

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Circle #123

SEARCH

continued from page 11

47XXX. Because of the Turner syndrome, Haley is very small (32 inches tall and 23 pounds) and has no ovaries.

Haley has never eaten food; she drinks a predigested formula. At 10 months, she had a fundoplication (a surgical procedure to correct severe gastroesophageal reflux) and a gastrostomy (insertion of a g-tube for feeding). She chokes on her formula and saliva.

Haley has bleeding stomach ulcers and a paraesophageal hernia from extremely forceful internal pressure. Because of this pressure, 29 g-tubes have blown out of her stomach with 10 cc of fluid still in the balloon. Haley recently had a pyloruplasty (repair of the valve between her stomach and small intestine), but this procedure did not help her pressure. Bile now comes up through her tube, along with her stomach contents. We must vent the tube constantly.

Despite Haley's many problems, she is bright, alert, happy and mobile—thanks to braces and years of physical therapy to deal with hypotonia (low muscle tone). She has talked since she was eight months old and now converses in complete sentences.

We would like to communicate with other parents who have a daughter with Turner syndrome along with other diagnoses or difficulties, or with anyone who needs to vent their child's g-tube constantly, with contents continuously rushing back.

J.E., Pennsylvania

EDITOR'S NOTE: These organizations may be able to provide useful information and support regarding some of Haley's disabilities: Turner's Syndrome Society of the U.S. (15500 Wayzata Blvd., #768-214, 811 12 Oak Ctr, Wayzata, MN 55391; 612/475-9944) and Opitz Family Network (P.O. Box 516, Grand Lake, CO 80447; 303/627-8935).

Chromosomes 2 and 14

One of my two-year-old twin daughters has been recently diagnosed with a balanced translocation of chromosomes 2 and 14. Unfortunately, nobody seems to know much about these two chromosomes, so no one can answer our questions about her future. She has developmental delays, especially with her speech.

I would like to hear from another parent whose child has this type of chromosome abnormality.

P.B., Virginia

Bowing of Tibia and Fibula

Our two-year-old son, Jacob, was born with posterior medial bowing of the tibia and fibula (the two bones of the lower leg). We are desperately searching for information and other families dealing with this condition.

B.A., Florida

Partial Trisomy 15

Our son, "TJ," has been diagnosed with partial trisomy 15. Our doctor says this condition is fairly rare. We would appreciate any information from any source.

T.N. , Florida

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Circle # 74

RESPOND

Swinging Objects

C.T. (April 1995) has a 10-year-old son with Down syndrome. He also takes Synthroid for hypothyroidism. Since he was a baby, he has had a tendency to focus on objects that he can hold and swing around. Often, as he swings the object, he talks to himself, and sometimes, he spins in circles. At these times, he seems to "zone out." As he has gotten older, these behaviors have increased. C.T. is looking for any suggestions for trying to understand and lessen the frequency of this behavior, if not eliminate it altogether.

My four-year-old daughter has Down syndrome. She also loves to focus on objects and swing things in front of her eyes, while babbling and talking to herself. It is quite easy to interrupt her to get her back to task, but I, too, am concerned about how she can "zone out" everything.

She has been doing this since she was a baby, and the pediatricians and development specialists say not to worry. They tell us to keep distracting her or take away whatever she is swinging and show her what the object is used for. But I am still very worried.

A specialist told me that because my daughter is affectionate and can make eye contact, her behavior indicates self-stimulation, not autism. She has also undergone careful evaluation of her hearing and vision.

If you get any suggestions that seem to work for your son, I would appreciate hearing about them.

G.R., Newfoundland, Canada

■ We are the parents of a seven-year-old boy, Brett, who has Down syndrome. Our sons would probably get along great! Brett also enjoys swinging one of his toys and spinning in circles. While doing this, he often babbles or hums. At these times, like your son, Brett seems to "zone out" everything around him.

We try to offer Brett different things to do so we can distract him from spinning this toy. He has gotten to the point where he becomes very angry and screams when we take the toy away from him. I would be very grateful for suggestions or ideas.

K.S., New York

Omphalocele

L.S.,(April 1995) has a six-month-old daughter who was born with a large omphalocele; her entire liver was outside of her body. She was looking for information about the development of children born with this condition including growth patterns, motor skills, weight gains/losses and feeding difficulties.

My three-year-old son, Adam, was born 10 weeks premature with an omphalocele. His entire liver was concealed in a thin sac on the outside of his stomach. When he was two days old and only three pounds, doctors performed surgery to "push" his liver back in. He has a fairly large scar on his stomach and no belly button, but he is healthy as can be. He has *no problems* related to the omphalocele. We have had a few stitches work their way out over the years, but that hasn't been a problem.

As a totally unrelated condition, my son has cerebral palsy. He is very verbal, and totally non-ambulatory. Someday, I will have to explain to him why he doesn't have a belly button. For some reason that seems so inconsequential compared to trying to explain why he can't walk. We don't know what caused the omphalocele, and probably never will. I am pregnant with my second son now and pray every day for a healthy full-term baby.

L.V., Wisconsin

Dealing with Seizures

D.R. (May 1995) has a son, Christopher, who is almost three years old. He has cerebral dygenesis, meaning that roughly half his brain is gone. He has developmental delays, hypotonia, slightly clubbed feet, farsightedness and a seizure disorder that is mostly controlled by Dilantin. But when Christopher does have a seizure, he stops breathing. D.R. wanted to know how other parents deal with seizures, especially how they sleep at night.

Our son is five and, like Christopher, also has a seizure disorder. He has developmental delays, hypotonia and visual impairment, but is otherwise very healthy and happy. Currently, his seizures are fairly well controlled by medication.

Like Christopher, our son has difficulty breathing during and after a seizure. He doesn't actually stop breathing, but his breaths are very shallow and irregular. His seizures always happen while he is sleeping. We had to call the paramedics during the last one because he had such a hard time recovering from it—he was struggling for air and his heart rate remained high. After they administered oxygen, he relaxed and went back to sleep. We have since obtained in-home oxygen to use in these situations; this has given us amazing peace of mind.

To answer your question about how we sleep at night, we still use a nursery monitor. I am a light sleeper—differences in my son's breathing, or the smacking sounds he makes when he is having a seizure, wake me up. Mother's intuition may also play a role; sometimes I've been in a deep sleep and I've begun to dream that he is somehow in trouble or that someone is trying to hurt him—only to wake up and find him having a seizure.

Our son has a fear of going to sleep by himself. This fear developed about the same time his seizures started. So anytime he has a fever, I will just sleep in his room. Although some people may frown on the practice, I see nothing wrong with sleeping in the same room as your son if that makes everyone more comfortable. We fought that solution for several years, but after many tears and sleepless nights, we finally decided it would be better for everyone.

C.A., Arkansas

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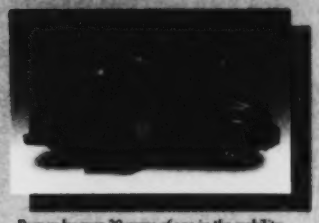
B R A U N



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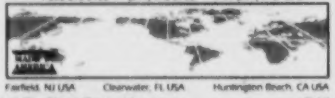

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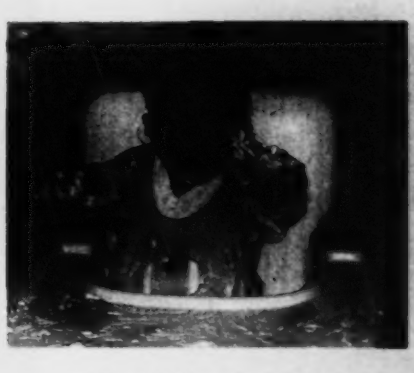
Familiar Faces



At least he wore a bib! As 28-month-old Matt Boysen demonstrates, a simple household item, like Dad's shaving cream, can provide hours of fun. In fact, Matt needed only a few minutes to cover himself—and everything else he could get his hands on—in the foamy stuff. Matt, who has Down syndrome, lives with parents Dirk and Carey in College Station, Texas.

The camera caught seven-year-old Jennifer Ann Carter with curlers in her hair! Well, at least she'd gotten her nails painted before Mom started snapping away. Jennifer, who lives in Clearwater, Florida has nonketotic hyperglycinemia, a rare metabolic disorder. Doctors said she would not live to six months of age; she's 10 now.

Tina Dockray, 10, of West Milford, New Jersey, enjoys her family's annual vacations to Wells Harbor, Maine. She especially enjoys the water, even though she has to be careful not to get her tracheostomy wet. When not on vacation, Tina, a third-grader, enjoys reading, writing and playing t-ball. Tina, who has congenital myotonic dystrophy, is the first child with disabilities to play on a regular t-ball team in her hometown.

It takes more than a sudden downpour to dampen the spirits of a vacationing Justin Oneall Justin, who has cerebral palsy and hails from Mt. Vernon, Georgia, loves to travel; his favorite word is "go!" When the weather turned soggy during a visit to Zoo Atlanta, 20-month-old Justin was having too much fun to leave. So, mom Regina rushed to purchase and put together some makeshift rain gear—a stroller-mounted umbrella, a rain hat and a couple of plastic bags.

Yeeee-hah! Cowgirl Kylie Linton Moullen, 4, of Bellingham, Washington, gets a giggle out of trying to fill her daddy's boots. Kylie's mom, Marilyn, says doctors consider Kylie a "mystery." She has a seizure disorder, some rare metabolic deficiencies, a sensory integration disorder and dysautonomia. "But," says Marilyn, "she's every bit as goofy as the next kid."

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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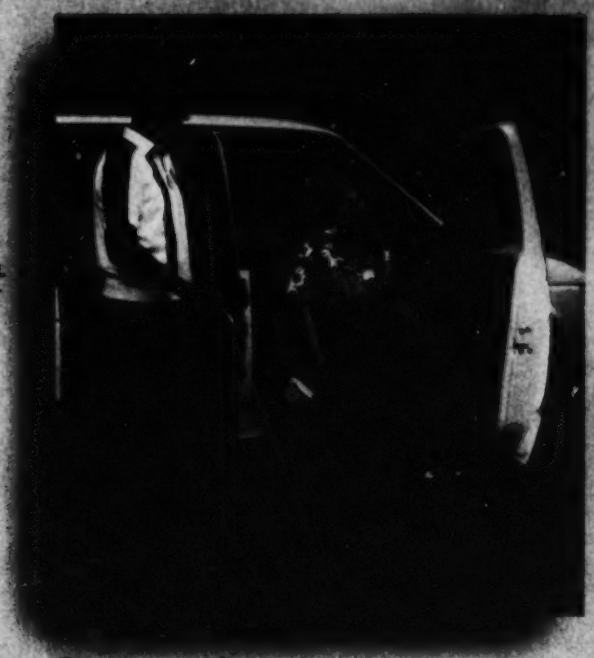

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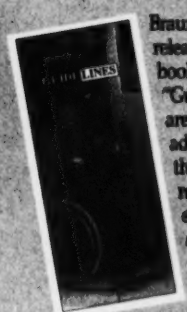

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by John O'Hare

In the neonatal intensive care unit, John held Ryan for the first time. Ryan, one day old, had already undergone his first surgery.

As I watch you sleep, all curled up clutching your little panda bear, my heart swells with love and pride. I look back on how far you've come in your short life, and I think about all the obstacles and challenges you have faced and conquered. I don't think you will really ever know what a little hero you are to your mom and dad.

When Dad arrives home from work, Ryan, 9, gets in some "lap time."

When I first saw you, just nine short years ago, I was torn between so many different emotions. I was thankful, but I had so much fear and apprehension because the doctors had told your mom and I to prepare for the worst. You had beaten so many odds just by being here, but we still didn't know what the future would hold. We were not even able to hold you before you were whisked away.

The first time your mom was allowed to hold you, she could not hold back the tears. You were so little and fragile, but so beautiful. Those first few days had been so hard—watching you lying there in your little bed and being unable to hold you. We could only visit a few times each day, but we lived for those times. You were so tough, and as you grew stronger, your will to fight amazed all the doctors and nurses.

I look at you now, sleeping so peacefully. We had such fun today. Your mom sometimes asks if it bothers me that you can't do so many things other little boys your age can do—things like playing ball or running with other children. I always tell her no; it is such a joy just to have you, and to be able to do all the things we do together. You enjoy life so much and are so happy doing the things you can do; I see no reason to be sad. I only have to recall your silly, crooked little smile as we rode the roller coaster at the amusement park last weekend, or think about how excited you get whenever you see a train go by. You may not be able to do some things, but you live life to the fullest, little boy.

I could stand here watching you for a long time, but I'm afraid I may awaken you. I once read that special children are a blessing from God. I believe that now. Always remember, you are loved so much. Sleep peacefully, little Ryan; we'll see you in the morning. **EP**

John O'Hare, 43, lives in Charlotte, North Carolina with his wife, Diane, and son, Ryan, 9. John is a 20-year veteran of the Charlotte-Mecklenburg Police Department, where he currently holds the rank of Captain.

Diane, a registered nurse, works weekends, so Saturdays and Sundays are "buddy days" for father and son—as John puts it, "a wonderful opportunity for me to develop a very special relationship with a very special child."

There's nothing like a bedtime story—especially when it's read by Dad!

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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Heather Whitestone

"Yes, you can!"

On September 17, 1994, 21-year-old Heather Whitestone became the first woman with a disability to be crowned Miss America. Whitestone, an accomplished ballerina, has been profoundly deaf since the age of 18 months. After the new Miss America is crowned in September 1995, Whitestone, who currently logs more than 20,000 miles a month in public appearances, will return to Jacksonville State University in Alabama to continue her studies in accounting.

Last April, during a visit to Boston, Whitestone took the time to speak with EXCEPTIONAL PARENT *associate editor Kim Schive. The following was adapted from that interview.*

Heather played with a new toy on Christmas morning, 1974, the day her family discovered she was deaf.

When I was 18 months old, I had a high fever and almost died. The doctors gave me a medication that caused my deafness. My parents figured out I was deaf soon after I came home from the hospital. My mother dropped some pans in the kitchen; it scared everybody in the family except me. I just kept playing with my toys.

At first, my mother felt angry. She didn't want me to be deaf. She wished she could take my deafness for herself. But then she started to look at the situation as an opportunity for creative ideas. She began to investigate methods of communication and education, like the oral approach [speaking and reading lips], total communication [using sign language along with speech] and the acoupedic approach, which means training a child to listen with a hearing aid.

My mother visited classrooms where different methods were used. She was most impressed with acoupedic training, because the children in those classes came right up to her and talked to her. She felt free to communicate with them. When she met students who used sign language, she felt awkward. She had to use an interpreter to communicate with them. She wanted me to be able to communicate with everyone, so she chose acoupedic training.

Heather, 5, attended a regular kindergarten with hearing children.

"I knew I was different."

I went to a regular kindergarten with hearing children. I knew I was different. I was the only deaf student. I stayed in public school through fourth grade. Then I told my mother I wanted to go to school with other deaf children.

Before going to Central Institute for the Deaf (CID) in St. Louis, I had never met other deaf kids—maybe just one little girl, who was younger than me, at the speech therapist's office.

When I arrived at CID, I had mixed feelings about seeing all the other deaf children. In one way, it felt very strange.

I lived in the dorm. At first I loved it. It was like having a slumber party all the time. But it was stressful, too, because there were so many children around all the time.

The other students were interesting; they came from all over the United States and the world. I had friends from Mexico, South America and Kuwait. It broadened my horizons.

My best friend was from Canada. She was a very determined girl. I admired her because she never let anybody stop her. But some of the other deaf students had very low self-esteem; they used their deafness as an excuse all the time. They would say, "You're deaf, you cannot do it." I didn't like to be around those kids.

CID was a great school. My first year there, I advanced two grade levels. The school had very small classes—like three or four students in each—and the teachers knew the best way to communicate with me.

The real world

When I was 14, I returned to public school. It was ninth grade, the beginning of high school. I remembered some of the other students from when I was in public school before. But they had changed so much. There was a lot of peer pressure; kids fooled around with drugs, drinking and sex. I didn't want to do any of those things. Because I chose to be true to myself, I did not fit in with the crowd.

The second problem was that the other kids were a little bit afraid to communicate with me. Even though they saw me speaking, they thought I would not understand them. They would say, "Oh, Heather is deaf. I have to sign to her! She would never understand me!"

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So some of the kids learned some sign language. Two of them would keep coming up to me and signing to me—without their voices. It was a little embarrassing. They were only seeing my deafness, not my heart and not my abilities. I was like, "I'm sorry, but I don't know sign language!"

High school was lonely. In those four years, I had only three friends. I practically had to beg a guy to take me to the prom and homecoming

Heather remembers her years at a hearing high school as lonely. "But," she said, "It taught me what I needed to do to survive in the real world."

dance—and now I'm Miss America!

But I don't regret that I went to a hearing high school. It taught me what I needed to do to survive in the real world. I learned to take responsibility for educating people who don't understand my problems. Let's face it—the world has more hearing people than deaf people. When I go to the airport, I don't see deaf people. When I order a hamburger at McDonald's, I don't order my hamburger from another deaf person.

"HIGH SCHOOL WAS LONELY. I PRACTICALLY HAD TO BEG A GUY TO TAKE ME TO THE PROM AND HOMECOMING DANCE."

Yes, I get lonely. That's part of having a disability. Anyone with a disability probably experiences some loneliness every day. And I get tired of always having to educate people about how to communicate with me. Sometimes, I hate it... I hate it, but that's the real world.

continued on page 24

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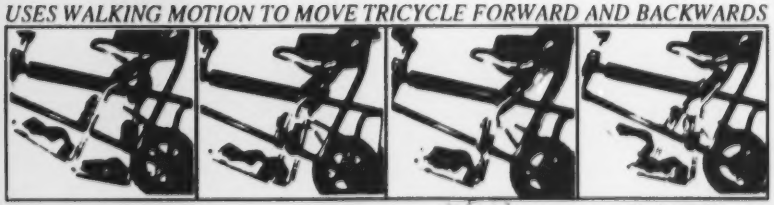

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continued from page 23

Becoming Miss America

One of the first local pageants I entered was the Miss St. Clair [Alabama] pageant. I didn't win anything, probably because my first interview with the judges did not go well. They acted so awkward. I thought they did not like me because of my deafness. I was sure that was why I did not win.

Later, my family watched a videotape of the interview. They told me, "Heather, we don't believe you lost because of your deafness; it was how you handled it. You did not master the situation."

My family was right. I had not told the judges what to do in order to communicate with me.

Two weeks later, I was in the Miss Jacksonville State University (JSU) pageant. This time, I had a wonderful interview because I told the judges how to communicate with me. I asked them to look at me, and to talk slower so I could read their lips. The judges felt at ease with me after I explained this. And I won the pageant!

As Miss JSU, I had the chance to go to the Miss Alabama pageant. I won first runner-up. I went back to Miss Alabama a second year—and I was first runner-up again! But the third year, I won. Finally, I had my chance to compete for Miss America; but in Miss America, you only get one chance.

During the first seven months of 1995, Heather has logged more than 20,000 miles a month in her travels as Miss America. She spent the morning of June 10 meeting children at the SHHH (Self-Help for Hard of Hearing People) convention in Dallas, Texas, where she helped young Lauren Thompson adjust the Miss America crown for a picture perfect pose. (Photo courtesy of Oticon 4 Kids.)

Some people say I won Miss America because I am deaf, but that's not true. I believe I won Miss America because of my determination and my education. In fact, I was not even the first deaf contestant. Six years ago, Miss

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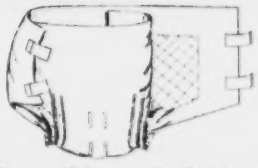

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Washington [Jennifer Wall, 1989] was the first deaf contestant at the Miss America pageant. She did very well; she finished in the top ten.

Making a difference

As Miss America, I hope that I can make an impact on some people. I want to help people with disabilities believe in themselves, and I also want to raise awareness among people without disabilities.

So far, I have received more than 5000 letters. One was from a deaf girl, the only deaf girl in her high school. She said that before I won Miss America, she was not sure people would be willing to be open to people with disabilities. But after I won Miss America, she began to have more confidence in herself. And this year, she was nominated to be her school's homecoming queen.

A friend of my mother told me a story about a little girl in her neighborhood. The little girl, a hearing girl, decided she wanted to dress up as Miss America for Halloween. And her mom helped her dress up with a white gown, white shoes, a crown and a scepter. She had everything, and she looked beautiful. But she cried because her costume was not right. She told her mother she couldn't go out trick-or-treating—because she didn't have a hearing aid!

Yes, you can!

Whenever I talk to kids, I tell them, "I believe in you. You can do whatever you want to do; you can do it!" One time I said that to the kids I met while visiting a school for children with disabilities. Some of the kids had severe cerebral palsy and couldn't move much; some had mental retardation.

Reporters were following me around while I talked to the kids. Later, the press was very hard on me. They asked, "Why did you tell those kids they can do it? Look at them! They can't do anything."

At the time, this made me feel really bad. But later I was thinking about it and I thought, "If I were one of those kids, I would want to hear that someone believes in me."

My mother always believed in me. She always was there for me—whenever I succeeded, whenever I failed. And she always said, "You can do it, Heather. Yes, you can!" **EP**

Mom writes about Heather and ballet...

Heather began taking dance classes at the age of five. By nine, she was an accomplished ballerina. "I encourage parents of children with disabilities to give their children opportunities for activities with other children after school," she says. "It was very important to me."

Fortunately for Heather, she had her dance, because the rest of her daily life—at least during the school year—consisted almost entirely of... long hours of speech therapy and schoolwork. Any recognizable progress in those areas came slowly and at a great price.

Dancing was different. For Heather it was pure joy. I think one reason she enjoyed her dance class was because students seldom had to speak or answer questions out loud, so she didn't feel so different. She fit into the crowd and felt just like everyone else out on the dance floor. She believed she could dance just as well as anyone else in her class—maybe better.

I knew there were still some people who had a hard time understanding how or why a deaf child would be taking ballet. I vividly recall a conversation I overheard early one Saturday morning during a dress rehearsal for a recital. Sitting by myself in a row of seats out in the auditorium, watching Heather's little troupe practice their numbers, I caught just enough of something said behind me that I began to listen carefully. I didn't turn around to look, but two mothers I didn't know, who evidently also had daughters up on stage, were talking about Heather. "She's deaf, you know. Can't hear a thing. I don't know what she's doing in dance class anyway; it's a shame Tracy let her in. I just know she's going to mess up tonight and ruin the whole program."

I had a thing or two I wanted to say to those ladies. But for once I simply bit my tongue and let it go... By this time, no one could have said anything to make me pull Heather out of her ballet. I saw how much it meant to her. And I felt it invaluable for her to have something that was all hers. Something she didn't do because it was expected or required. Something she did purely for love.

Dance performances also gave Heather a welcome chance to shine in public. My family—my parents, Stephanie and Michael—would drive all the way down from Birmingham for her recitals. They always made such a fuss over her afterwards that I'm sure Heather thought she'd been the star of the show. I felt that affirmation was good for her.

Another one of the joys Heather got out of her ballet I didn't fully understand until her teacher Jeannette Sutherland told me this story... In class one day she asked the children to tell one thing they did when they wanted to irritate their brothers or sisters... When Heather's turn came, she walked to the front of her class and got this incredibly mischievous grin on her face. Then she explained that if she wanted to make her sisters, Stacey and Melissa, really mad, she waited until they were watching their favorite Saturday morning cartoons, then she'd begin dancing back and forth across the room. She demonstrated with a little twirl and laughingly told her classmates, "I go front TV, they get mad and yell."

As Jeannette related the story, I couldn't help but laugh. I'd seen Heather pull that stunt many times, though I'd never realized she'd done it deliberately to aggravate her sisters. I'd always thought she was just so engrossed in her dance routines that she was oblivious to what her sisters were doing, or to their words when they would yell at her—"Get out of the way, Heather! Who do you think you are, anyway! Miss America or something!"

Taken from the book, Yes, You Can, Heather! by Daphne Gray. © 1995 by Daphne Gray. Used by permission of Zondervan Publishing House. This book is available at your local bookstore, or by calling (800) 727-3480.

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Genetic Counseling

PART ONE "The science is the easy part"

by Naomi Angoff Chedd

Charlie and Jennifer Ross were just over 30 when they got married five years ago. They were healthy, gainfully employed and eager to start a family. Jennifer was thrilled when she got pregnant "the first time out of the gate," as she put it. She spent the next eight months reading all the right books, decorating the nursery and cutting back to a part-time work schedule. Her labor and delivery went smoothly; both Charlie and Jennifer felt they were the luckiest people on earth.

When their daughter Alyssa was diagnosed with cystic fibrosis (CF) two months later, it was like a bolt from the blue—"an eight on the Richter scale," says Charlie. They had heard of the disease only vaguely, and neither knew of anything similar in their family backgrounds. They didn't know where to turn for help, until their pediatrician suggested they consult a genetic counselor. "A what?" asked Jennifer.

Genetic counselors are the savvy and eloquent people you see being interviewed as part of news reports on major breakthroughs in our knowledge about the cause or treatment of a devastating illness or the discovery of a cancer-causing gene. But for Charlie, Jennifer and Alyssa, genetics is more than a talk show topic. The Rosses, and thousands of other families, are the people behind the headlines; they know all too well that advances in genetics are making life harder and easier at the same time.

What is genetic counseling? The mother of a six-year-old with Down syndrome put it well when she said, "In two one-hour sessions, our counselor taught me everything I wished I had remembered from Biology 101, Psychology 101 and Philosophy 101." Genetic counseling draws on knowledge from these fields—and others—in an effort to provide the most accurate, up-to-date information on the causes and treatment of genetic disorders, the tests available for identifying them, a possible prognosis for a child with a genetic condition and the prospects for future pregnancies.

Who does genetic counseling?

After Alyssa was diagnosed, the Rosses consulted a certified, Master's-level genetic counselor, one of about 1200 in the United States. But a family with a child who has a genetic condition may also receive useful information from their family practitioner, obstetrician, pediatrician, a neonatologist, a nurse with a subspecialty in genetics or a geneticist with in-depth knowledge of their child's particular condition.

Although different professionals provide genetic counseling in slightly different ways, they all agree it is a process of communication. "We help families look at the big picture, not just the medical diagnosis," says Kathryn Spitzer Kim, director of clinical placements for Brandeis University's genetic counseling program, one of only 20 such programs in the country. "We also talk about the social, educational and financial considerations."

About this series:
It is impossible to discuss genetic counseling without acknowledging its far-reaching medical, legal, moral, economic, political and religious implications. However, the two articles in this series will be limited to the practical aspects of genetic counseling—what it is, who does it and how it can enhance or perhaps further complicate the lives of parents, professionals and especially our children.

Part II will focus on some available pre- and post-natal tests and profile several families—the chances they took, the choices they made and the lives they now lead.

A good genetic counselor should have first-rate knowledge of genetics. But he or she should also be able to communicate that knowledge in easy-to-understand language. And, according to Barbara Bowles Biesecker, genetic counselor and section head at the National Center for Human Genome Research, National Institutes of Health, genetic counselors must be able to listen as well as talk. "People are terrified when they get a diagnosis," she explains. "They often ask, 'Why did this happen?' They already know the scientific explanation; what they are really asking are the more soul-searching questions—'How will I cope? Will I be able to love and accept this child?' Genetic counseling is much more complicated than explaining percentages. Actually, the science is the easy part."

Charlie and Jennifer agree. "We didn't want to spend the rest of our lives searching for genetic clues in our family backgrounds; we wanted to find help, people who understood what we were going through. We just wanted to talk."

More than prenatal testing

Possibly the most important thing families can get from a genetic counselor is time—time to process a lot of information, time to ask questions, time to consider options and, perhaps, time to grieve the considerable losses they may experience.

A genetic counselor can provide a tremendous amount of information about local and national resources. He or she may

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also be able to explain the practical implications of recent research results. Jennifer says, "Every time we hear anything about CF, we get so excited. We hang on every word, hoping for a cure. Our counselor has explained that while science is a lot closer, they're not about to knock at our door with the cure tomorrow."

Although a clinical geneticist or other doctor can also explain the medical consequences of a particular disorder or disease, physicians tend to be less neutral regarding options in the event of a prenatal diagnosis; this is particularly true of physicians working in managed health care organizations. In some cases, they may make the recommendation to terminate a pregnancy. After all, it is not to the economic advantage of an HMO to have a lot of kids being born with special (translation: "expensive") health care needs. A genetic counselor will not—or at least, should not—be directive.

Another advantage of working with genetic counselors is that they are often familiar and comfortable with conditions other medical professionals rarely see. While your pediatrician might see two children a year with your child's disability, a genetic counselor may see two a week. "One of the best things our counselor did was hook us up with other parents. Nobody can understand what we're going through except other CF parents," says Jennifer.

If your child does not have a diagnosis, you are not alone. One-third to one-half of children with abnormalities have no diagnosis. Perhaps your child's condition does not yet have a name, or nobody is willing to call his or her particular group of symptoms by a name, because it may not be a precise fit. But a genetic counselor may still be able to help you tap into resources, organizations or support groups.

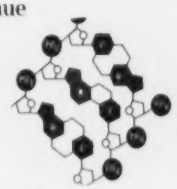
Should you see a genetic counselor?

Different families seek genetic counseling for different reasons. A couple with a newly-diagnosed infant or young child, for example, will probably want a comprehensive explanation of the child's condition and likely prognosis. They may also want to know the chances of this or another birth defect occurring in future pregnancies.

A family with an older child or more than one child may be thinking about reproductive issues for all their children—for example, the odds that a sibling without the condition is carrying the defective gene.

Betsy Gettig, a 15-year veteran in the field and past president of the National Society of Genetic Counselors, says that couples or individuals can expect genetic counselors to provide three important things:

- *Reproductive information:* What are the chances of certain diseases or genetic conditions occurring in a current or future pregnancy? Are there ways to reduce the risks? Are there successful pre- or post-natal treatments?
- *Prognosis:* What is the likely course of a given disease or condition? How will a given child be doing in one, five or 10 years? While no clinician can predict the future with absolute certainty, they usually can provide the range of possibilities.
- *Advocacy and support:* People sometimes make decisions that aren't accepted by family members, friends or even personal physicians—trying an experimental treatment, for example, or choosing to continue or terminate a pregnancy. Genetic counselors try to ensure that their clients make carefully considered choices based on accurate information; then they support them in the decisions they make.



According to Philip R. Reilly, M.D., clinical geneticist, lawyer and president of the Shriver Center for Mental Retardation, the following people may benefit from consulting a genetic counselor:

- Families in which there is a known genetic disorder, such as cystic fibrosis, Huntington's disease or hemophilia.
- Couples who come from the same ethnic group, when that group is known to have a higher incidence of certain disorders. Tay-Sachs disease is common among Ashkenazi Jews, for example, and one in 12 African-Americans carries the gene for sickle cell anemia.
- Families in which there have been multiple miscarriages, stillbirths or a childhood death from unknown causes.
- Women older than 34 who are pregnant or planning a pregnancy.
- Relatives—especially siblings—of a child with a genetically-transmitted disorder.

Genetic counseling provided Charlie and Jennifer Ross with the information and support they needed after their daughter's diagnosis. Almost three now, Alyssa is doing well, and although they understand the range of possibilities for Alyssa's future, Charlie and Jennifer think "she's going to be around for a long, long time." They add, "We're even thinking she might like a little sister or brother." **EP**

Naomi Angoff Chedd is a member of EXCEPTIONAL PARENT*'s editorial staff.*

How do you find a genetic counselor?

Your pediatrician or the geneticist at your HMO or hospital may be able to refer you to a qualified genetic counselor. Your state's department of public health may also be a good resource. Or contact one of the following organizations:

National Society of Genetic Counselors
233 Canterbury Dr
Wallingford, PA 19086-6617
Requests for information and referrals must be received in writing. NSGC does not maintain or disseminate information about specific genetic disorders.

Alliance of Genetic Support Groups
35 Wisconsin Cir #440
Chevy Chase, MD 20815-7015
(800) 336-4363
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Provides referrals to genetic counselors, support groups and other resources nationwide.

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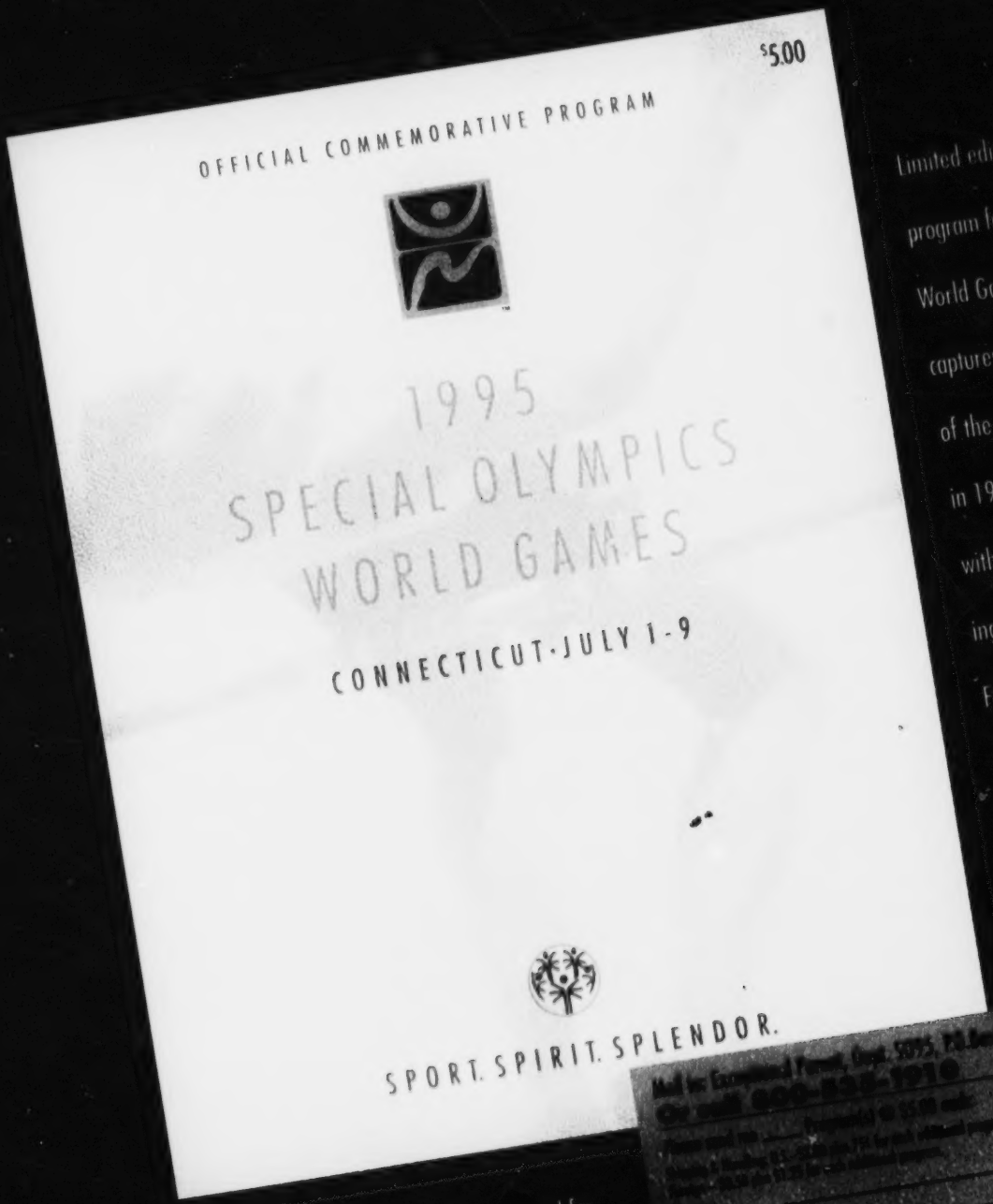

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The Value of Prenatal Testing

by Alysoun Reichard

Like many women who identify themselves as opposed to abortion, I used to think prenatal testing was only for women who believed in abortion. In the past few years, however, my perspective has changed dramatically.

When I finally became pregnant after six years of infertility, I worried that I would miscarry, but I never really worried that my child might have a problem. I had an alpha-fetoprotein (AFP) test because I had taken a fertility drug and was curious to know if I was carrying twins. When the results came back elevated, I still wasn't concerned. I figured it was either twins or an error.

There was never any doubt in my mind that I wanted my baby. So when my daughter was diagnosed with spina bifida during the follow-up ultrasound, in the nineteenth week of my pregnancy, I made it very clear I had no intention of terminating.

Over the next few weeks, I was repeatedly asked to explain my strong desire to have this child. The infertility specialist told me I should be able to conceive again, if that was my concern. But that wasn't it. What it really came down to was this—we did not conceive our child to play football with her. We didn't keep her because we were afraid we would "burn in hell" if we aborted.

Alysoun Reichard and daughter Heidi, 20 months, enjoyed the fall foliage at Sleeping Giant Park in Hamden, Connecticut.

We kept her because we loved her, we wanted her, and there wasn't anything that we wanted to do with a child that she would not be able to do.

The counselor's role

I fully believe that genetic counselors should remain neutral on the issue of abortion. They should offer families a clear picture of the implications of their findings, and then allow them to make their own decisions. However, I do not believe that rattling off a list of intimidating medical conditions constitutes offering a clear picture.

I also believe that it is inappropriate for a genetic counselor to speculate—even when asked—about what he or she would do in a given situation. First of all, it is a question that is impossible to answer. By 24 weeks gestation, a pregnant woman has already developed a relationship with her baby. She is showing; everyone knows she is pregnant. She has felt the baby move. The counselor may feel able to weigh the decision objectively. However, in the same situation, she might find herself considerably less objective.

Mostly, however, I feel that a woman needs to make this decision within the context of her own value system. In her darkest hour, whatever she decides, she needs to know it was her own decision. This is a mighty burden to bear. A counselor may be tempted to try to help her shoulder it, but that is not part of the counselor's role. The counselor's responsibility is to give the woman as much information as possible to help her make this decision on her own. If a woman truly seems unable to decide, I believe it would be more appropriate to bring in an additional advisor—a social worker perhaps—rather than violate the neutrality of the genetic counselor.

As prenatal testing becomes increasingly routine, genetic counselors will find themselves serving more and more women who are either ambivalent about, or opposed to abortion. These women deserve an approach that is respectful of their values. Their babies deserve the benefits of early diagnosis, but they will not have that benefit as long as women are distrustful of genetic counseling. One of the most common questions I am asked about my experience is, "Did they try to get you to have an abortion?"

Fortunately, I am able to answer emphatically, "No, they did not. They were very supportive of my decision." But the very frequency of the question underscores the distrust that exists.

An "informed decision"

Though I was never pressured to terminate my pregnancy, I was asked repeatedly whether or not anyone had discussed my options with me. Until I

continued on page 30

Heidi—aka "Winnie-the-Pooh"—celebrated Halloween 1992 with preschool buddies (from left) Brian Smith and Taylor Valentine.

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continued from page 29

reached the third trimester of my pregnancy, every new practitioner I met—and there were quite a few—seemed to feel it was his or her personal responsibility to establish that I was making an "informed decision."

I would like to suggest a simple solution to this potentially upsetting problem. I believe there should be one member of the team—whether it be the genetic counselor or the social worker—who is designated to verify that the patient has reached an informed decision. Once a decision has been made, a bright red sticker should be placed in a prominent position on the patient's file, indicating to all other practitioners that they do not need to bring up the subject. If doctors fail to see a sticker on a woman's folder, they can simply inquire as to whether she has had the opportunity to talk with the counselor, or social worker, or whomever the designated person may be.

When a woman is undecided, she is sometimes offered the opportunity to meet with the family of an affected child. I have already stated that I am opposed to abortion, so you may be surprised to hear that I feel such a meeting to be totally inappropriate. If a family has decided to keep their baby, I would be more than happy to meet with them, but I could not possibly meet with them before that time.

A fashion tip from five-year-old Heidi—If you simply can't choose between two equally lovely hats, wear both!

First of all, there is absolutely no way I could be neutral. My daughter is my pride and joy. Beyond that, no two children with spina bifida, or any other disability, are alike. My daughter's condition may be very different from that of their child. Also, I would feel as if I was giving this family the opportunity to judge the value of my daughter's life in order to decide whether they should give their own child life. As my daughter got older, I would worry that she might pick up on that aspect of these meetings.

Still, the opportunity to see living, breathing children—rather than hearing a list of medical conditions, could be very helpful to families in the decision-making process. The ideal solution may be for a neutral party to make a videotape of a number of children with a given disability. The video could cover the range of possible disabilities, and to paint a balanced picture of everyday life, the children could be shown in the community and at home. The distance afforded by a videotape would also

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protect the family making this difficult decision. They would not be under any pressure to make a decision to please anyone but themselves.

Yet, if I were to meet with a family struggling with this decision, there is one thing I would want to say: All new parents look at their tiny babies and wonder if they will be able to rise to the task of caring for them. Parents of children with disabilities are no different. Who can blame them if they question their ability to cope with their children's problems? Yet just as millions of new parents cope with their responsibilities every year, thousands of ordinary couples also rise to the challenge of caring for children with disabilities.

It's better to know

At the time of Heidi's diagnosis, I was working in a large office full of women. Many of my coworkers told me how brave they thought I was. No one came right out and said they would have aborted, but I know a lot of them thought it.

It's such a contrast with what we hear now. When people see our bright, happy little girl and find out that we knew about her condition before she was born, they say things like, "What a tragedy it would have been for you to have aborted this beautiful child!"

And Heidi is beautiful. She has a gift for happiness. When we go to the mall, people see her tooling around in her little purple wheelchair, and they smile at her because she's so cute. Then, I frequently see a cloud come over their faces as they realize something must be wrong with her. But the cloud soon gives way to another smile as they realize it doesn't matter, because this child is obviously happy just the way she is.

I do sympathize with women who say that they would never want to be faced with such a decision. I hear women say that knowing ahead of time would ruin the remainder of the pregnancy.

I will admit that my pregnancy was a very difficult time, but I will always be grateful that when I finally gave birth to my daughter, it was in a setting where she could get the best of care from the moment of her first breath, and that my husband and I were fully prepared to welcome her into our lives with open arms. At the time of a prenatal diagnosis, it may be hard for families to see the value of the opportunity they have been given, but ultimately I believe families and their children benefit most by knowing about problems as early as possible. **EP**

Alysoun Reichard lives in Kettering, Ohio with her husband, Dave, and daughter Heidi, 5. She writes about issues related to children with disabilities; one of her recent articles, on accessibility, appeared on the op-ed page of the DAYTON DAILY NEWS. This article was adapted from a speech delivered at a genetic counseling symposium held at Brandeis University (Waltham, Mass.) in June 1993.

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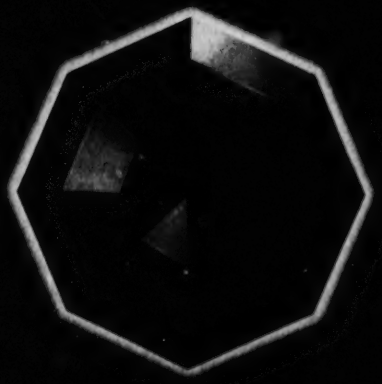

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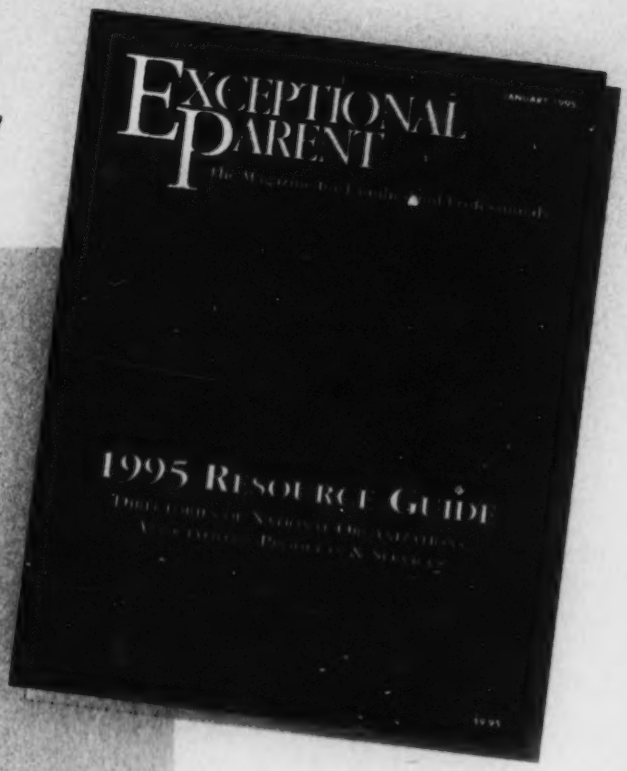

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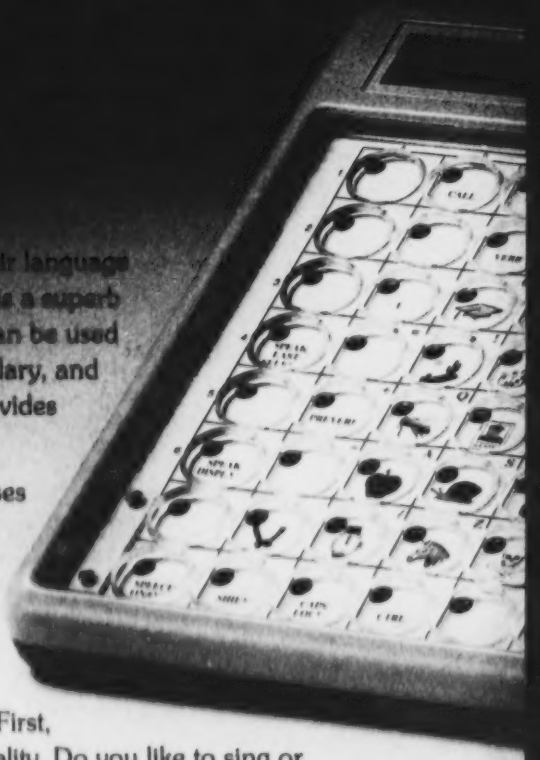

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Circle 669

Health

A New Twist to "Playing Doctor"

by Rick Rader*

For years, patients have been the cornerstone of medical education. Because one can only learn so much from a textbook, "real live people" are used to teach physical signs, procedures, history-taking and physical examinations. Every physician has a story to tell about one or two memorable "teaching patients," who imparted never-to-be-forgotten pearls of wisdom.

I'll never forget my first encounter with a "patient-consultant," as they were known in the London teaching hospital where I trained. I was given 10 minutes to examine this woman's cardiovascular system and come up with a working diagnosis. The woman was quite talkative, especially after she recognized my distinctive New York accent. As I tried to listen to her heart, she babbled on and on about her relatives in Rochester, New York—perhaps I knew them? I couldn't hear a thing through the stethoscope, but I could hear the professor's footsteps coming down the hall, stopping at every cubicle and asking each student to describe their findings. I was starting to panic; I didn't have a clue what this woman's heart was trying to tell me.

Just before the professor got to my cubicle and pulled the curtain back, this little blue-haired lady leaned forward and pulled one rubber stethoscope tip out of my ear. "You won't go wrong with mitral valve prolapse, Yank," she whispered.

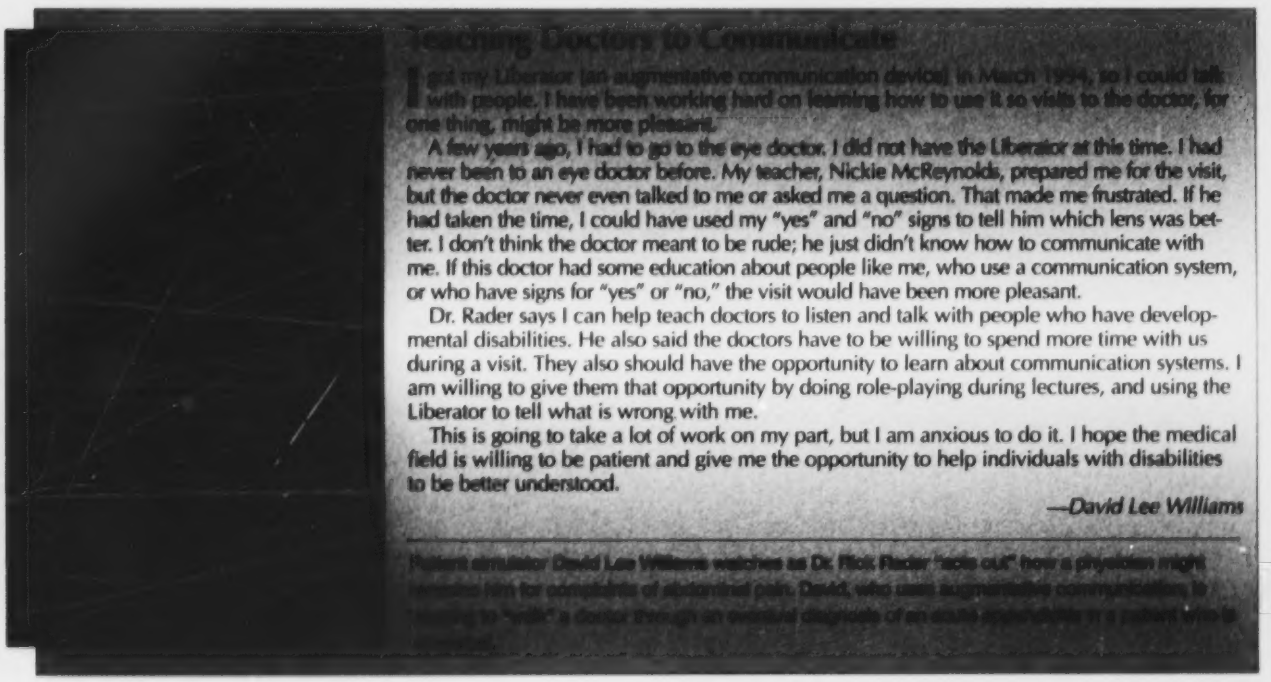
At that split second, I turned to the sound of the professor entering the cubicle. "Might it be mitral valve prolapse?" I asked. The professor raised his left thumb like a 1940's Royal Air Force pilot who just heard his Spitfire roar to life. My first experience with a "patient-consultant" was memorable, to say the least.

Patient simulators

Unfortunately for medical education, the "textbook case" is usually seen only in a textbook. Patients—being people, and sick people at that—are subject to a variety of personalities and individual peculiarities. In addition, diseases announce themselves individually and assume a host of presentations.

These variations of patient and disease have often been cited as obstacles in teaching. How "fair" is it to have three medical students examine three different patients and be tested on their

* *My gratitude to these colleagues whose ongoing interest and contribution to this program has made it possible: Mike Cook, executive director, Orange Grove Center, Chattanooga, Tenn.; Dr. Bob Clark, associate dean & director, University of Tennessee College of Medicine, Chattanooga Unit; Jenny Chase, Amy Khalifa and Nicki McReynolds, special education teachers, Orange Grove Center, Chattanooga, Tenn.; Kelly Bankston, David Lee Williams and Kawanna Williams, patient simulators, Institute of Developmental Medicine, Orange Grove Center, Chattanooga, Tenn.*



Teaching Doctors to Communicate

I got my Liberator (an augmentative communication device) in March 1994, so I could talk with people. I have been working hard on learning how to use it so visits to the doctor, for one thing, might be more pleasant.

A few years ago, I had to go to the eye doctor. I did not have the Liberator at this time. I had never been to an eye doctor before. My teacher, Nickie McReynolds, prepared me for the visit, but the doctor never even talked to me or asked me a question. That made me frustrated. If he had taken the time, I could have used my "yes" and "no" signs to tell him which lens was better. I don't think the doctor meant to be rude; he just didn't know how to communicate with me. If this doctor had some education about people like me, who use a communication system, or who have signs for "yes" or "no," the visit would have been more pleasant.

Dr. Rader says I can help teach doctors to listen and talk with people who have developmental disabilities. He also said the doctors have to be willing to spend more time with us during a visit. They also should have the opportunity to learn about communication systems. I am willing to give them that opportunity by doing role-playing during lectures, and using the Liberator to tell what is wrong with me.

This is going to take a lot of work on my part, but I am anxious to do it. I hope the medical field is willing to be patient and give me the opportunity to help individuals with disabilities to be better understood.

—David Lee Williams

Patient simulator David Lee Williams watches as Dr. Rick Rader "acts out" how a physician might examine him for complaints of abdominal pain. David, who uses augmentative communications to "talk" to a doctor through an eventual diagnosis of an acute appendicitis in a patient who is

PHOTOGRAPHY BY DENNIS WILKES

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findings? To "level the playing field," and to ensure that students are equally exposed to the same clinical scenarios, medical educators created the "standardized" or "simulated" patient.

"Patient simulators" are actors who are trained in the clinical presentation of a particular disease or condition, and hired to play the part of a patient presenting his or her complaints to the medical student. With in-depth understanding of the condition, the actor can direct a student's history-taking to reflect the responses a "real" patient would provide.

Patient simulations have proven to be an effective method for teaching medical history-taking, differential diagnosis, medical communications, medical manners and elicitation of signs and symptoms ("signs" are any objective evidence of a disease as opposed to "symptoms," which are the sensations and complaints reported by the patient).

Patient simulators with disabilities

At Chattanooga's Orange Grove Center, a community agency providing educational, medical, residential and vocational services to almost 800 individuals with developmental disabilities, we have taken the concept of the "standardized patient" one step further. We are using individuals with developmental disabilities and mental retardation as patient simulators.

Most medical students and residents—even many seasoned physicians responsible for patient care at a teaching hospital—have had little if any exposure to people with disabilities. Most medical school graduates have seen a 90-minute slide show on dysmorphology—abnormal anatomic development; this slide show is the closest encounter most medical students ever have with developmental disabilities.

Because we believe that physicians need to learn to communicate with their patients who have disabilities, Orange Grove's educational division, the Institute for Developmental Medicine, created the Developmental Disabilities Patient Simulator Program. We believe this is the first undertaking of its kind.

Teachers recommended students for the program on the basis of their personality, disability, health care experience, willingness to participate and ability to learn about and teach various acute (sudden-onset) conditions. Our first challenge was to explain the idea of "playing sick" and to make sure participants understood that this sort of role playing was appropriate only in the teaching setting. Again, teachers helped us to impart this concept—the concepts of "real" and "pretend" are difficult ones. Our next step was to teach participants the script. Although the program is still fairly new, we are pleased with the response we have gotten from both doctors and "patients."

"Why don't you take off my jacket?"

We currently have three patient simulators in the program; each one can present a different medical condition. David Lee Williams, 27, who has severe cerebral palsy (spastic and athetoid quadriplegia), presents a "hot appendix." David's role requires an appreciation for the transition from periumbilical (belly button) pain to pain in the lower-right quadrant of the abdomen and the classic "McBurney's point" tenderness, appearing in the area of the abdomen that corresponds with the normal position of the appendix. David, one of our best standardized patients, communicates solely through augmentative communication, using an electronic, symbol-based communication device mounted on his wheelchair. Accurately diagnosing appendicitis through this unique means of communication provides the clinician with a unique challenge.

Another standardized patient plays the part of an individual

Kelly Bankston, 14, presents an upper arm contracture to an Erlanger Medical Center resident participating in the Developmental Disabilities Patient Simulator Program. In Kelly's first "performance," she suggested that a nervous intern might get a better "feel" for the contracture by first removing her bulky ski jacket.

with a closed head injury from a car accident, resulting in dizziness and blurred vision. Kawanna Williams, 19, has cerebral palsy, mental retardation, microcephaly (smaller-than-average head) and decreased truncal tone (abnormal tension in the main part of her body). Kawanna gives an Academy Award performance as she invites the clinician to compare their conclusions of the neurological exam against Kawanna's "usual abnormal" neurological signs. Kawanna's portrayal of a patient with a head injury presents a unique challenge because—as a result of her disability—even without an injury, she would not demonstrate "normal" neurological signs.

Watching 14-year-old Kelly Bankston invite interns to examine her upper-arm contracture and come up with a diagnosis would put a smile on anyone's face. Kelly has cerebral palsy (spastic quadriplegia), mental retardation and thoracolumbar kyphotic scoliosis (curvature of the spine). During her first "performance," Kelly stopped the nervous new doctor in the middle of her examination and suggested she would get a "better feel" for the problem if she first removed Kelly's bulky ski parka. One can be certain that doctor will never make *that* mistake again. Kelly's engaging charm provides medical students with the realization that children with developmental disabilities and mental retardation are not just kids with "small-print syndromes" (a reference to their relative importance in medical books), but first and foremost, they are children with dreams, curiosity, humor and frustrations—just like the physicians themselves.

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Dr. Rick Rader (standing) presents patient simulator Kawanna Williams to attendees at medical grand rounds at Erlanger Medical Center. Kawanna plays the role of a patient with closed head injury resulting from a motor vehicle accident.

Doctors

I like to see the doctors and I like to talk to them. They are nice. They check your braces and they see if your braces are rubbing anywhere. I like them because they make you feel better.

My doctor will see me again in four months. I am excited to see him when he walks in the door.

I'm happy to help doctors learn how to take care of me. I want to teach them how to talk to me. The doctors ask my Uncle Paul all the questions. I want them to ask me, because I am the one who knows how I feel.

I want to learn better what to say to the doctors when I make believe I hit my head in the car.

—Kawanna Williams

continued from page 37

This opportunity to introduce neophyte clinicians to real children with developmental disabilities is the "raison d'être" of the program. We are not trying to conduct tutorials in pediatric developmental medicine, but we hope we are expanding the perspectives of each young doctor so he or she will have the confidence, curiosity and consideration to look forward to seeing that child or adult with special needs who will someday come through the office door.

We want the next generation of physicians to appreciate the fact that individuals with developmental disabilities also get the flu, earaches, sprained wrists and cancer. They need to be treated with the same respect, dignity and thoroughness as the other patients in the waiting room. With patient surrogates like David, Kelly and Kawanna we're hoping we can help doctors to not only care *for* these kids, but also to care *about* them. **EP**

Rick Rader, M.D., a member of EXCEPTIONAL PARENT's Editorial Advisory Board, is the director of the Habilitation Center and The Institute for Developmental Medicine at The Orange Grove Center in Chattanooga, Tennessee. In addition to his post-graduate clinical training in internal medicine, Rick studied medical anthropology and bio-behavioral medicine. Rick's work at Orange Grove involves research into robotics, virtual reality, bioengineering and medical education as applied to individuals with developmental disabilities.

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The Friendly Skies

Transportation no barrier to medical care

Trudy and Steven Nelson had raised three children on their farm in Columbia, Missouri, but as the kids began leaving home, they found themselves unprepared to face an "empty nest." The Nelson's fourth child, Caleb, was born in 1987, shortly after the birth of their first grandchild. One year later, Caleb's younger sister, Stephanie, joined the family.

Trudy and Steven were prepared to reacquaint themselves with 2 a.m. feedings, but their son's birth presented additional challenges. Caleb was born with achondroplasia, a form of dwarfism, and had a number of complex physical and medical needs.

Eight-year-old Caleb Nelson (right) visits the cockpit of Mel Potter's six-seater Cessna 414. Because Caleb has had a vertebral fusion in his neck near the brainstem, he can fly only in a pressurized aircraft like this one; he could not survive the traumatic pressure conditions in some other small planes. Potter (left), an Angel Planes pilot from Wisconsin, is president of Potter & Son, a company that cultivates cranberries for Ocean Spray.

By the time Caleb was four, the Nelsons had made 25 trips to Baltimore, Maryland to visit medical specialists. Trudy and Steven used credit cards to pay for airline tickets. These transportation costs, added to already substantial medical bills, strained the family's finances. In 1991, they were forced to file for bankruptcy.

But Caleb's medical problems continued. Last summer, faced with the need for another trip to Baltimore, the Nelsons discovered Angel Planes, a national organization of volunteer pilots, based in Las Vegas, Nevada, that could arrange round-trip transportation for the family.

A reason to fly

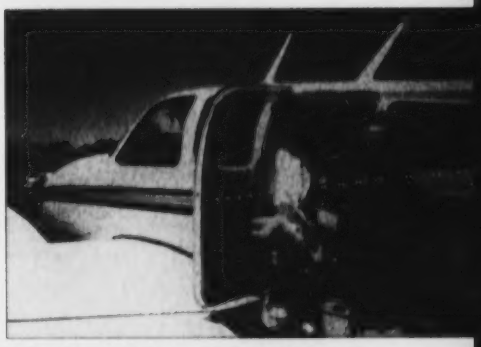
Angel Planes and other organizations like it (see sidebar on page 40) were established to ease the financial burden families experience when caring for a child or other family member with special medical needs. These organizations aim to ensure that no individual is denied necessary medical care because a family is unable to pay for transportation. Through volunteer pilot organizations, many children and adults can be flown to distant medical centers for treatment, completely free of charge. Pilots donate their time, expertise, fuel and, usually, their own planes. Some programs also provide seats on commercial flights, using the donated frequent flier miles of business travelers.

Pilot Tracy Winslow has completed 33 Angel Planes flights since 1990. "I get a lot more out of it than I put in," he attests. Winslow, a 34-year employee of Chevron Oil, learned to fly on glider planes while working in Iran. "After retiring," he says, "I didn't know what to do with my pilot's license or four-seater Cessna 172. Angel Planes has given me a reason to fly and something meaningful to do with my retirement. It gives me tremendous personal satisfaction that I could get involved in such a purposeful project at this stage in my life."

Bill Segal, volunteer pilot and New England flight coordinator for Air Life Line, a similar organization, explains his eight-year involvement with the group in similar terms—"Most pilots like an 'excuse' to fly. Others, like myself, feel blessed to be able to fly and to have this great gift we can offer people who need our help."

"Peace of mind"

In May, Caleb underwent his nineteenth surgery—a cranial expansion at Johns Hopkins Medical Center in Baltimore. Because Caleb's skull had stopped expanding, this surgery created the necessary space in his cranial cavity to allow his brain to grow.



Angel Planes pilot Luther Luttrell (right) of Ohio flew six-year-old Cassie Millis (left) and her family from Erie, Pennsylvania to Little Rock, Arkansas for a medical consultation.

Cassie has tibia hemomelia (one leg shorter than the other). Doctors in her home state had recommended amputation for the shorter leg; Cassie is now undergoing a leg-lengthening procedure in another state.

Back home in Columbia, Missouri, Caleb is enjoying his summer and looking forward to entering third grade at Fairview Elementary School. Caleb enjoys bike-riding, tae kwon-do, computer games, outdoor yard work and play-

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Anthony Staley (foreground), 3, of Winnemucca, Nevada, has traveled with his mother and older brother to many out-of-state medical specialists. Air Life Line provided transportation for many of these trips. Anthony has multiple disabilities.

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Pilot Tracy Winslow flew Brandon Moncrief, 4, from his home in Las Vegas, to California's UCLA Medical Center in Santa Monica. Brandon has Crohn's disease.

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ing with his puppy, Jordan.

According to his mom, Caleb considers every trip on a twin engine aircraft a grand adventure. But to Steven and Trudy, these trips are something more. "Angel Planes has been wonderful," Trudy says. "It's hard enough just worrying about how you're going to make it through all the operations and medical expenses. Having someone out there who is willing to take care of the transportation gives parents a real peace of mind." **EP**

—Michele San Filippo

Volunteer Pilot Organizations

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Except where noted, flights may originate anywhere within the continental United States. As noted following some listings, certain organizations have limits on the distance of a single flight, but most of these groups will try to help families plan longer trips through relays with other organizations.

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705

Selective Dorsal Rhizotomy

The term "cerebral palsy" is used to describe many children and adults who have some sort of brain injury ("cerebral") resulting in problems with movement ("palsy"). Since there are different types of cerebral palsy, adjectives describing specific types (for example, "spastic" or "athetoid") usually precede the more general term, cerebral palsy, and describe the way an individual's nervous system and muscles function.

Doctors may also describe people with cerebral palsy in terms of the part of the body primarily affected—for example, diplegia (both legs), hemiplegia (one side of the body) or quadriplegia (arms, legs, face and trunk). They may also classify an individual's disability as being mild, moderate or severe.

Children with spastic diplegia have spasticity (increased muscle tone or tension) that mainly affects their lower extremities. They tend to stand on their toes and bring their legs together in a crossed—or "scissored"—position. If children with spastic diplegia learn to walk, they typically drag their feet and have limited endurance for walking long distances. They may also have muscle tone problems in the upper parts of their bodies, but these problems will be less severe than in their lower extremities.

In children with spastic quadriplegia, spasticity affects all parts of the body. Spasticity in facial muscles can lead to problems with eating and speech. Spasticity in the trunk can result in seating difficulties. In general, children classified as spastic quadriplegic are less likely than children with spastic diplegia to be able to learn to walk.

Children with *spastic diplegia*, who are *able to walk independently* and *willing to cooperate with the rigorous physical therapy* that will follow the surgery, are considered ideal candidates for selective dorsal rhizotomy (SDR). Since a child's intellectual ability is related to his or her understanding of the procedure and motivation for therapies, clinicians will also consider a child's intellectual ability in weighing the decision to proceed with surgery.

Spasticity and walking

The brain is an incredibly complicated structure. Any explanation of its workings is likely be vastly oversimplified, unable to account for the nuances of human behavior as well as differences between individuals. Furthermore, we still don't know everything about the workings of this complex organ. But with those limitations in mind, let's take a look at brain function with regard to walking, because improving a child's ability to walk is one of the main goals of SDR.

The many parts of the brain are connected by a vast network of nerve fibers. Specific parts of the brain control various body functions. In walking, the part of the brain that controls voluntary leg movements (the motor cortex) initiates "messages" to stimulate the appropriate muscles and to control the

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Go For It!

In the summer of 1991, when I was nearly 13 years old and about to enter the seventh grade, my parents and I decided to find out more about a procedure we had heard about called selective dorsal rhizotomy (SDR). We visited the Spasticity Management Clinic at Children's Hospital and Medical Centers in Seattle, Washington. At first, the doctors weren't sure whether this procedure would be a good one for me because I was doing quite well already; I had only mild spasticity in my legs. But the orthopedic surgeon's opinion was the clincher; he said I could have the surgery if I wanted it.

My parents told me I could make my own decision, and I decided to go for it The surgery was scheduled for February 13, 1992.

I was a little nervous as the date approached, however, we were kept busy with clinic appointments, countless medical tests and a tour of the hospital. We got up at 4 a.m. on the day of surgery. The last thing I remember of that day was one of my doctors joking with me in the pre-op room. For the next eight days I remained in the hospital, much is a blur. I know I did start some physical therapy and I even got back to my schoolwork.

After I was discharged from the hospital, I could not go home because I couldn't ride in a car. My mom and dad took turns staying with me at Children's Village, which is a few blocks from the hospital. During my three weeks there, we went to the hospital for physical therapy twice a day; and, of course there were daily visits to the ever-present hospital schoolroom! For the next two years, I participated in a lot of physical therapy. I started with four times a week after school, with a couple of at-school sessions thrown in for good measure. As time passed, I worked my way down to once a week, then once every two weeks.

The Aas family—(clockwise from upper left) Sheila, Dave, Ryan, Sean and Dan—outside their Maple Valley, Washington home, about a year after Ryan's rhizotomy surgery.

I think the results of my surgery were very good. Now, I walk with a much more normal gait. Before surgery, I walked with a crouched, turned-in gait. I have before- and after-SDR videos, which really point out the difference. I'm also more agile on my mountain bike.

If I had this decision to make over again, I would choose the rhizotomy. In the future I'm pretty sure I will feel the same.

—Ryan Aas
Maple Valley, Washington

Ryan Aas, 16, lives in Maple Valley, Washington with his parents, Sheila and Dave, and younger brothers Dan and Sean.

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responses of these muscles. These messages are sent from the brain to the leg muscles through nerve fibers (called motor nerves or motor neurons) that travel from the motor cortex, through two other areas of the brain, and then down the spinal cord. Within the spinal cord, other fibers connect with the motor nerve fibers and relay the messages to the muscles of the legs and feet that are involved in walking. At about the same time, another set of nerve fibers in the legs and feet, known as sensory nerve fibers, send messages back to the brain about muscle tension and sensation (pain, touch and position).

"Muscle tone" refers to the amount of tension (or resistance to movement) in a muscle. When the tone in all muscle groups is balanced, movements are smooth. Too much tone—known as "spasticity" (or sometimes, "hypertonia," a more general term)—causes movements to be stiff and awkward.

Spasticity seems to be the result of brain damage that interferes with messages from the brain, which are intended to stimulate and control muscle tone or tension. In the case of spasticity, however, the control mechanism is impaired, so messages from the brain stimulate the muscles excessively; this causes too much tone, and the resulting movements are stiff, slow and/or jerky.

Of course, the act of walking involves more than these interactions between brain and muscles. Balance is involved—this is regulated by a part of the brain known as the cerebellum; sighted individuals also get useful feedback through vision. Visual information enters the nervous system through the eyes and travels to the part of the brain involved in seeing (the occipital lobe). The occipital lobe is interconnected in complex ways with the other parts of the brain involved in walking. In fact, walking, like many other "ordinary" activities, involves the coordination of an intricate system that allows many parts of the body to "communicate" with each other via the brain.

When to consider SDR

SDR is not usually performed until a child is at least three years old—and more commonly, seven years old or older. In fact, clinicians often wait until a child is three years old before identifying the type and severity of his or her cerebral palsy. This is because the brain cells and the connections in the brain may change as the child matures.

Even when a child's diagnosis is clear, it can be difficult to predict the progress an individual child might make with non-surgical therapies. (For more about non-surgical alternatives to SDR, see *Ask the Doctor*, page 46.) However, children with cerebral palsy and a resulting delay in the development of "motor skills," usually begin to walk by about age seven if they are going to learn to walk. Also, a seven-year-old child with at least average intellectual abilities will be able understand the purpose of surgery, and will probably be motivated to cooperate with the extensive physical therapy that follows.

Evaluating "Success"

It's been seven years since our son, Sean, now 12, had his rhizotomy. As I reflect on Sean's surgery, his recuperation and the ways he has changed since that time, I recognize that I still have very ambivalent feelings about the outcome.

The team of surgeons and therapists working with us did a thorough job of evaluating, screening and educating us about the procedure. I was very careful not to expect too much from the surgery. Sean was not a "walker"—he was not even a "sitter"—so ambulation of any kind was not a goal. His spasticity was so strong, however, that it was often difficult just to dress him, hold him or even get him into his wheelchair. I thought the rhizotomy would make some of those things easier, and the surgeons concurred.

The Chambers family—(from left) Hank, Sean, Reid and Jill—enjoy kayaking on the bay near their San Diego home.

The post-surgery plan was for Sean—and therefore me, too—to remain in the hospital for three to four weeks, primarily to facilitate the two to three hours of daily therapy considered essential to the success of the surgery. Needless to say, this was very stressful for the whole family. Following the surgery, Sean was writhing in pain; even the intravenous morphine seemed only partly successful at making him more comfortable. A couple of days later, Sean developed double pneumonia. Though I was a veteran of surgeries and hospitalizations with Sean, my heart was breaking; I just hoped it would all be worth it.

Time passed as we faithfully dedicated ourselves to the many hours of therapy. Months later, after comparing pre- and post-surgery evaluations and videotapes, the team pronounced Sean's rhizotomy "a success." Five years down the road, I'm not so sure. Before the surgery, Sean was able to use his extension to help in weight-bearing for transfers; now, he can't. I see no measurable gains in functional skill areas. His fine motor coordination—needed for feeding and typing—has not improved; nor does he have improved balance or strength for sitting, rolling or "combat crawling." Yes, his spasticity has decreased, and his legs "scissor" less, but even that improvement was most noticeable after the hip surgery he had a few years after the rhizotomy.

This brings me to my basic dilemma in evaluating the "success" or "failure" of Sean's rhizotomy. We will never know what his course of development would have been without the procedure, so we can't say for sure whether his improved speech, for example, was a result of, or totally unrelated to, the rhizotomy. Would his extension and tone be worse today without the surgery? Maybe... maybe not. Would he have had more difficulties with his hips had he not had the surgery? Who knows?

As parents of children with disabilities, we make our choices based on what we believe will lead to a better life for our kids. Sometimes this means saying "yes" to surgery even though we know it will mean another trauma they—and we—don't need. Sometimes we say "no" to interventions, knowing we need time to regroup, reevaluate and try to stay whole. I do know that Sean is happier and healthier today than he ever has been, and if the rhizotomy contributed to that, it was worth it.

—Jill Chambers

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The evaluation process

Prior to surgery, the child should be evaluated by the team of medical professionals who will be coordinating his or her care, before, during and after surgery. The team will include a neurosurgeon (a surgeon who operates on the brain and nervous system), physical and occupational therapists, other clinical specialists and, often, the child's pediatrician. These team members, at least some of whom should have considerable knowledge about the growth and development of children with cerebral palsy, can make fairly good predictions about the likely outcomes of various surgical and non-surgical procedures. One key task for the team is to make sure that the child has spasticity rather than other types of movement limitations, such as dystonia (slow, rhythmic, twisting movements of the trunk, or of an arm or leg). Some children with quadriplegic cerebral palsy have both spasticity and dystonia, and may not be candidates for SDR.

The team also needs to measure the child's abilities to move his or her arms and legs and to perform various tasks such as sitting, walking and self-help activities. This measurement of the child's "functional abilities" before surgery can serve as a basis of comparison with his or her abilities after surgery.

The evaluation process is also the time when the team, the parents and the child can learn about the surgery itself; how the child is likely to feel before, during and after; and details of the intensive therapy that will follow SDR. In addition, it is

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Dad's Turn

I have to agree with Jill that we don't really know the usefulness of rhizotomy in children with cerebral palsy. Currently, several large studies are evaluating its effect, but it is still an unproved procedure. One of the difficulties in studying a new procedure is that we don't have two equal groups of children to compare. Every child with cerebral palsy has a "unique" cerebral palsy.

I don't know Sean's rhizotomy was a success, but comparing Sean to the hundreds of children with cerebral palsy I have cared for in my profession as a pediatric orthopedic surgeon, I believe his spasticity was decreased by the rhizotomy. Although he has had several later orthopedic surgeries, it is my impression that by lowering his spasticity, we have eliminated much of his posturing and extension. Current studies are showing that some children who have had rhizotomy surgery face long-term problems with scoliosis (curvature of the spine) and lordosis (sway back), so we're not looking forward to that.

Was rhizotomy worth it for our son, Sean? Can I recommend the surgery to my patients? These are hard questions to answer. That's why medicine is as much art as science.

—Hank Chambers

Jill Chambers is an advocate for her son, Sean, and other children with disabilities in San Diego. She is very involved in community activities. Hank Chambers, M.D., is a pediatric orthopedic surgeon at San Diego Children's Hospital and the University of California at San Diego. He also serves as the Chairman of the Advocacy and Parent/Consumer Relation Committee of the American Academy of Cerebral Palsy and Developmental Medicine. Hank and Jill live in San Diego, California with their sons Sean, 12, and Reid, 17.

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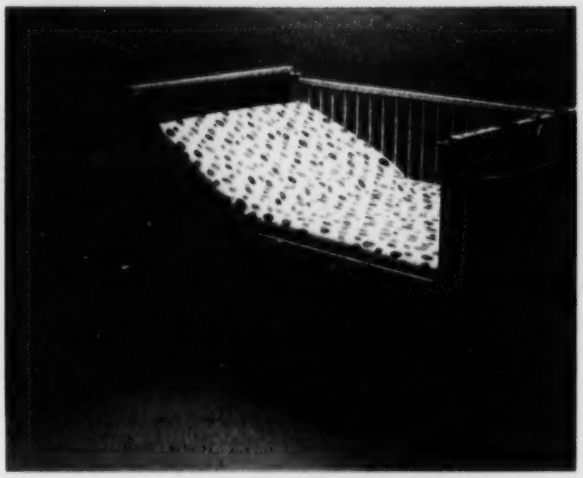

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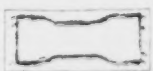

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essential that everyone discuss their expectations about the results. Some parents—and children—may have expectations that exceed those of the clinical team, who base their expectations on the results they have seen in similar children.

The team also needs to discuss the surgery's cost and its potential risks. In the United States, SDR and the intensive therapy that follows will cost $30,000 to $50,000. Some health insurance plans cover all or some of the costs involved. In Canada, the national health plan covers all costs.

Surgery always involves some risk—infection, unexpected bleeding or side effects of anesthesia. In SDR, there is the additional risk that the wrong nerves or too many nerves will be cut; this can cause new problems or further complications. Even when the appropriate nerves are cut, some children experience sensory abnormalities, such as numbness or tingling in some areas of the body. Sometimes, SDR seems to cause permanent weakness or reduced function.

The surgery

Before surgery, a child receives a general anesthesia, which makes him or her unconscious for the entire procedure. An anesthesiologist will monitor the child's bodily functions during the surgery.

The neurosurgeon begins by creating several small openings in the protective bone around the spinal column at different levels. Using a microscope, the surgeon can now see the motor nerve fibers, which originated in the brain, and exit the spinal cord, at different levels, to control movements of muscles and tendons in the hips, legs, knees, ankles and feet. The surgeon also has access to the sensory nerve fibers that relay messages from the muscles and tendons, through the spinal cord, to the brain.

To reduce spasticity, the neurosurgeon will cut some of the tiny rootlets that make up each sensory nerve fiber. Rootlets of motor nerves will not be cut, because this would prevent the muscles from receiving messages from the brain, leaving them with *no* tone—soft and unresponsive. It is unclear why cutting sensory nerve rootlets decreases spasticity, but doctors believe that decreasing the number of messages being sent from the muscles to the brain causes the muscle tone control system to work more effectively.

The surgeon goes through a careful and time-consuming process of applying electrical stimulation to the sensory nerve rootlets—one-by-one. By watching the way the muscle tone responds to this electrical stimulation, the surgeon can determine which rootlets seem to be associated with increased spasticity; those rootlets are cut.

The surgical procedure may take four to eight hours, even as long as 12 hours. It is a lengthy procedure because the team must take the time to be certain they are in the correct areas of the spinal cord. Then they must check each tiny sensory nerve rootlet to decide whether or not to cut it.

After the surgery

For the first three or four days after the operation, the child is confined to bed, lying on his or her stomach. The child will be sleepy and feel weak, especially in his or her legs. The child will have a long bandage on his or her back and is likely to experience considerable pain and discomfort. Doctors will prescribe pain medications. The child may feel nauseous or vomit; these problems are also treated by medication.

About 10 days after surgery, the stitches will be taken out of the child's back. After that, he or she will probably be able to be transported in a wheelchair.

In general, for the first four weeks, the child will receive physical therapy for up to two hours a day, five days a week. If the child has upper limb difficulties, he or she will also receive regular occupational therapy.

The child will be able to start physical therapy while still in bed, four to five days after surgery. However, for three to four weeks, he or she will continue to be weak and unable to tolerate sudden movements. As a result, the child will not be able to travel, and usually stays in a rehabilitation center, or in (or near) the hospital where the intensive therapy program will take place.

After the first month, the child can return home and attend school. Physical therapy—usually one hour a day, four or five days a week—will continue for five months. Then the child will continue physical therapy on a more typical schedule of one to three hours a week.

Over a period of three to six months, the child can be expected to gradually recover the abilities he or she had before surgery, and then begin to improve on these abilities. Some children make gains over their pre-surgery levels just three months after surgery. However, these gains may not last; some children do not seem to maintain their improved functional abilities over a period of years, even though their spasticity remains decreased.

Results?

Not all children improve after SDR. Some even lose ground. Although clinicians know that children with spastic diplegia are more likely to improve than children with spastic quadriplegia, they cannot predict which individual children will improve.

When improvement occurs, it may be different for each child. Following SDR, children with spastic diplegia may be able to stand with their feet flat on the floor; they may also make gains in walking, climbing stairs or self-care tasks. Some people even report improvement in skills that include upper body movements—probably related to an improvement in overall balance and stability. Children with spastic quadriplegia may improve in sitting or in their ability to transfer from one seated position to another. They may also improve in self-care skills and be less dependent on the assistance of others.

Cautions

SDR usually decreases spasticity. However, functional abilities (abilities to perform day-to-day tasks) do not always improve, even with less spasticity.

Some experts believe that improvements noted in some children following SDR may not result from the surgery. Rather, these improvements may be the result of the intensive therapy following the surgery and/or other factors such as developmental changes (changes that would have taken place anyway, as the

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child matured) or expectations of improvement that lead the parents and/or the child to have increased motivation and to make greater efforts to meet therapeutic goals.

When children do not receive intensive physical therapy following SDR, they are much less likely to improve. This seems to demonstrate that the therapy is essential, however, it does not prove the surgery is necessary. Some experts believe that less complicated procedures, such as certain orthopedic surgeries, can bring about similar improvements in standing or walking.

A recent fact sheet on SDR from the United Cerebral Palsy Research and Education Foundation states, "...there is still debate as to whether the long-term benefits of the procedure justify the risks, cost and expenditure of family resources. At this time, the available data indicate that SDR decreases muscle tone (spasticity), however, there are inadequate data to support or reject the usefulness of selective rhizotomy to improve long-term function..."

Research in progress

Three current research studies are attempting to determine whether SDR is critical to functional improvements. These studies will compare the improvement between children who receive *both* SDR and the intensive therapy, and similar children who receive the intensive therapy *without* the surgery. The results of these important research projects will be reported over the next two years.

Other current research shows that the use of small amounts of botulinum toxin may decrease the spasticity of some muscles for as long as four to six months. A medication, baclofen, can be safely administered into the spinal fluid. This research offers hope that spasticity reduction may someday become possible without surgery. **EP** —*S.D.K.*

The following medical experts contributed their experience and wisdom to this article. All are members of the American Academy for Cerebral Palsy and Developmental Medicine.
• Murray Goldstein, D.O., Medical Director, United Cerebral Palsy Research & Education Foundation, Washington, DC.
• John F. McLaughlin, M.D., Professor of Pediatrics, University of Washington School of Medicine; Director, Neurodevelopmental Program, Children's Hospital and Medical Center, Seattle, WA; Principal Investigator, "Selective Dorsal Rhizotomy: Effects in Cerebral Palsy," a five-year research study funded by the National Institute of Neurologic Disease and Stroke of the National Institutes of Health.
• Peter Rosenbaum, M.D., Professor of Pediatrics, Faculty of Health Sciences, McMaster University; Investigator, Neurodevelopmental Clinical Research Unit, Chedoke-McMaster Hospitals, Hamilton, ON, Canada; "National Health Scientist," an award to outstanding researchers funded by Health Canada.

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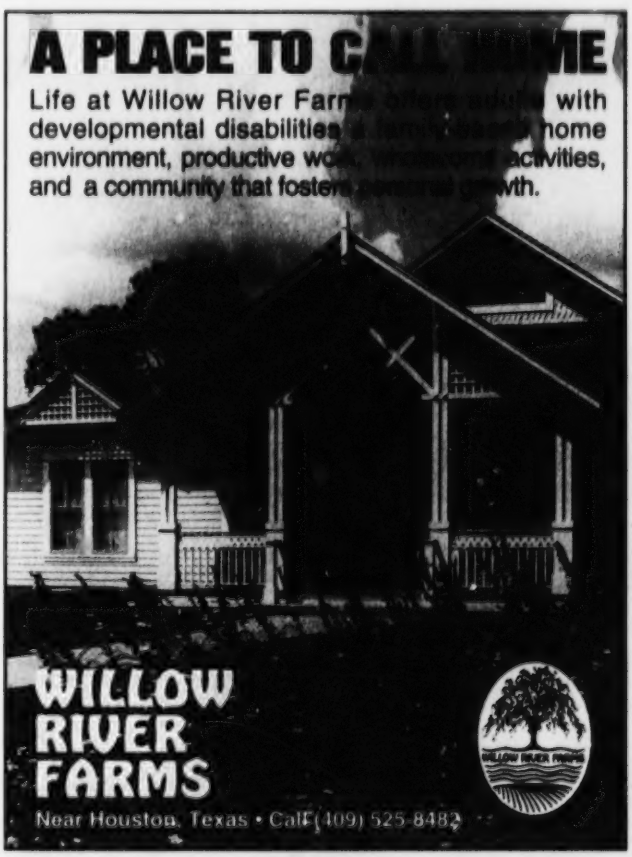

Circle #91

ASK THE DOCTOR

by David Hirsch, M.D.

Rhizotomy?

Q Our six-year-old son has a form of cerebral palsy called spastic diplegia; that is, he has severe increased muscle tone (spasticity) in his lower extremities. He has mild developmental delays, but no other neurological problems. He does not have contractures (abnormal shortening of a muscle due to increased tone, usually resulting in joints remaining in a flexed position), and he has not required any orthopedic procedures so far.

He is walking with the help of a walker, but it is a considerable effort. In fact, it frustrates him to the point where he would rather not use the walker. He receives physical and occupational therapies, which have been helpful.

Our pediatrician has suggested that he be evaluated for a rhizotomy procedure. I have heard good and bad things about this surgery. What do you think? Are there any other options available?

A The purpose of any therapy or surgical procedure for spasticity should be to improve the quality of life and self care. Selective dorsal rhizotomy (SDR) is a surgical procedure that has been used for many years to relieve spasticity of the lower extremities. In the last 15 years or so, there has been improvement in the technique, leading to more successful results. Increasingly, doctors are giving more thought to selecting the best candidates for the procedure, so the surgery will be done only on children who seem likely to benefit. This has also resulted in better overall results.

Based on your son's lack of other neurological or orthopedic complications, along with his and your motivation, your son may be a good candidate to be considered for SDR.

If the procedure is done by an experienced team of physicians and therapists, and considerable care is taken from candidate selection through follow-up, few complications typically occur. However, short-term problems with pain, urinary retention and sensory loss (from irritation or damage to the sensory nerve roots during the procedure) are not uncommon. Some recent studies also suggest the possibility of later complications such as decreasing range of muscle movement and hip dislocation; a small percentage of SDR patients will need additional orthopedic procedures sometime later.

My patients who have had SDR followed by intensive physical therapy, typically have had good results in terms of improvement in motor and self-help activities such as walking, toileting and transferring position.

Other treatment options

• *Physical therapy*—Aggressive stretching of tight muscles at involved joints is another option for the treatment of spastic diplegia. The goal is to increase range of motion and subsequent mobility. As the child progresses, his or her physical therapy will focus on muscle strengthening, gait training (improving the walking pattern) and, when appropriate, the use of adaptive equipment.

In range of motion exercises, done by or under the direction of a physical therapist, an adult moves one of the child's limbs, usually across a joint, in a repetitious and careful manner. Done properly, and often enough, range of motion procedures can significantly reduce the occurrence of complications such as contractures. Range of motion procedures are usually done in conjunction with the following treatment options:

• *Serial casting*—In serial casting, casts are used to reposition a joint or extremity. The first cast applied is intended to move the joint a certain amount. It is left on for a period of time—usually one to four weeks. Then, that cast is removed, and another cast—which moves the joint or extremity even closer to the normal position—is applied. This continues until the position of the joint or extremity has been altered.

• *Neuromuscular electrical stimulation* (NMES) is a newer procedure that has been used in conjunction with an aggressive, task-oriented physical therapy program. In NMES, very weak electrical currents are used to stimulate certain muscles. Initial results on some patients show promising results, but more study needs to be done.

• *Orthopedic procedures* for the treatment of spastic cerebral palsy have been done for some time and are well established. For example, children with cerebral palsy may walk on their toes because of tight heel cords. When less invasive procedures such as splinting, bracing and/or physical therapy have not relieved this problem, a surgical procedure may be done to lengthen the tendons in the child's heels. More recently, SDR and orthopedic procedures have been used to compliment each other in the treatment of spastic cerebral palsy.

• *Pharmacological treatment (medications)* may also be helpful. Most commonly used medications consist of benzodiazepines such Valium and Tranxene. Commonly used to treat anxiety, they also have the effect of decreasing muscle tone.

Dantrolene, a skeletal muscle relaxant, has a slightly different method of action. At this point, it has been used only in adults; like the benzodiazepines, it may cause excessive sedation.

One other medication, called Lioresal (baclofen), may be taken orally or intrathecally (administered directly around the appropriate area of the spinal cord). Researchers are currently studying the effectiveness of using this drug in this manner for the treatment of spastic cerebral palsy. **EP**

***In this column,** David Hirsch, M.D., a pediatrician and member of the EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mentions of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5006, (617) 730-8742 (Fax).

Health

This Doctor's Point of View

Knowledge and emotion go hand-in-hand

In December 1994, I spoke to a group of physicians at the Schneider Children's Hospital of the Long Island Jewish Medical Center about communicating difficult news to parents. After the talk, Arthur Weber, an orthopedic spinal surgeon, approached me to "confess" that he sometimes cried with parents about a child's complicated medical needs. A bit embarrassed, he joked that his physical size and manner made everyone think he was a "tough guy." Dr. Weber told me he had never discussed these emotional reactions with his colleagues or students.

I encouraged Dr. Weber to share his experiences with the readers of EXCEPTIONAL PARENT. In all the years I have been teaching professionals about communicating with parents, no one had ever asked me about professionals sharing their sadness through crying. I felt that both parents and professionals needed to hear about physicians' feelings.

At the end of June, Dr. Weber faxed a first draft of an essay. I called to tell him we wanted to publish it, and, because he had not directly addressed crying, I asked him to write a few more paragraphs.

On the evening of July 3, Dr. Weber operated on a patient until late in the evening. The next day, Dr. Weber suffered a fatal heart attack. Parts of this unfinished essay were read at his funeral. Dr. Weber had spoken to his friends and colleagues about his essay—he'd described looking forward to its publication with pride. Sadly, Dr. Weber will not be able to participate in the discussions his essay will stimulate. But these discussions will serve to honor his memory.

—S.D.K.

by Arthur H. Weber

My life as a doctor began with an internship on the cold windswept shores of the Bay of Fundy, in the city of St. John's, New Brunswick.

As inexperienced as I was, I loved those first few months. I spent much of my time caring for adults. Most injuries were repaired and most of the sick were either cured or went on to live out life's natural cycle. Although it is sad when older people die, it usually is not surprising, and can sometimes be a welcome relief from continued suffering. And besides, I was a witness to beginnings as well as endings. I delivered many babies; my life was full of flowers, chocolates and parties. Medicine was wonderful—it was everything I had expected it would be.

The third rotation of my internship involved training in pediatrics. I began working with children who had many different illnesses—everything from severe fever and upper respiratory infection to gastrointestinal illnesses. I got their flues, sometimes their fevers and even their diarrhea. But I was healthy and strong, and I could still function as a doctor. After a while, I became immune to their contagious illnesses.

During the next few weeks, I was exposed to two different categories of children—those with congenital disorders, who had lifelong structural problems, and those with life-threatening problems, such as cancer and leukemia. These children, especially those in the latter category, left indelible impressions that have molded my medical career.

This patient (left), a young man with Down syndrome, wanted to give surgeon Arthur Weber a kiss.

Children with terminal illnesses were brought to the hospital to live out the last days of their lives. The hospital took basic measures to make these days more bearable—we cooled their fevers, replaced their fluids, fed them and rendered the necessary supportive care. These tasks were easy to learn. The harder lessons came not from doctors or nurses but from parents. Parents with no medical knowledge showed an instinctual caring that went beyond medical treatment; I discovered there was no substitute for their comforting caresses and voices.

Families shared their suffering with dignity. When a child became weaker and more feverish, the bonds between child and parent tightened—almost as if those bonds could keep the inevitable at bay. Parents held their children in their arms as long as they could, walking back and forth along the long, dimly lit corridors of the hospital.

The frustration I felt as a physician was agonizing; I could not intervene in this suffering. My helplessness angered me, but I learned a great deal about love, hope and human interaction.

The days of that third rotation are now far behind me, but its lessons remain important. As a spinal surgeon I am often called upon to deal with

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children who have multiple disabilities. The most challenging are the children who require constant, unrelenting care. Their parents ask me to help them make their children's lives an iota better.

Seemingly small changes, such as helping children sit up independently, can be quite significant. Sitting up on their own, children eat and digest their foods better. They see the world differently, if they can see. Their hips do not dislocate. Their incontinence becomes more manageable. Their pressure sores become rare. Their breathing and pulmonary care improve, and their persistent upper respiratory infections decrease.

I used to wonder why the parents of these children didn't just quit, let go, stop treatment. Then I became a parent myself, and I began to understand things not only academically, but within my soul. As a physician I had been knowledgeable; as a parent, I gained understanding.

Dr. Arthur Weber with patient Barbara Rupp. Barbara, 12, has undergone 14 spinal surgeries.

This understanding has often proved crucial. For instance, spinal surgery and recovery are arduous, so I do everything I can to assist families as they make decisions about surgical procedures. I help them consider whether the benefit of treatment will outweigh the risks and difficulties. I help them ask the necessary questions: Does the child really need this operation? What would be the consequences of doing nothing? What are the chances of bringing this child through from surgery to recovery? Hours of reflection and planning may go into each case as we try to foresee potential problems and head them off before they occur.

I never operate without exploring all possible consequences of surgery. As a surgeon, I actively live through each operation, and do not feel well until my patient does. Being entrusted with a child's care is a special mission—a mission on which I have been grateful for the company of the children's exceptional parents. **EP**

Arthur H. Weber lived in Mill Neck, New York with his wife of 19 years, Valerie Weber, a physical therapist. Dr. Weber, a physician and surgeon, specialized in spinal disorders, reconstructive spine surgery and spinal trauma. In addition to his private practice, he was an assistant clinical professor at the Albert Einstein College of Medicine. He also taught at the State University at Stony Brook, New York Hospital/Cornell Medical Center and Long Island Jewish Medical Center. He published in several medical journals and was a diplomat of the American Board of Orthopedic Surgery. He suffered a fatal heart attack on July 4, 1995. He was 52.

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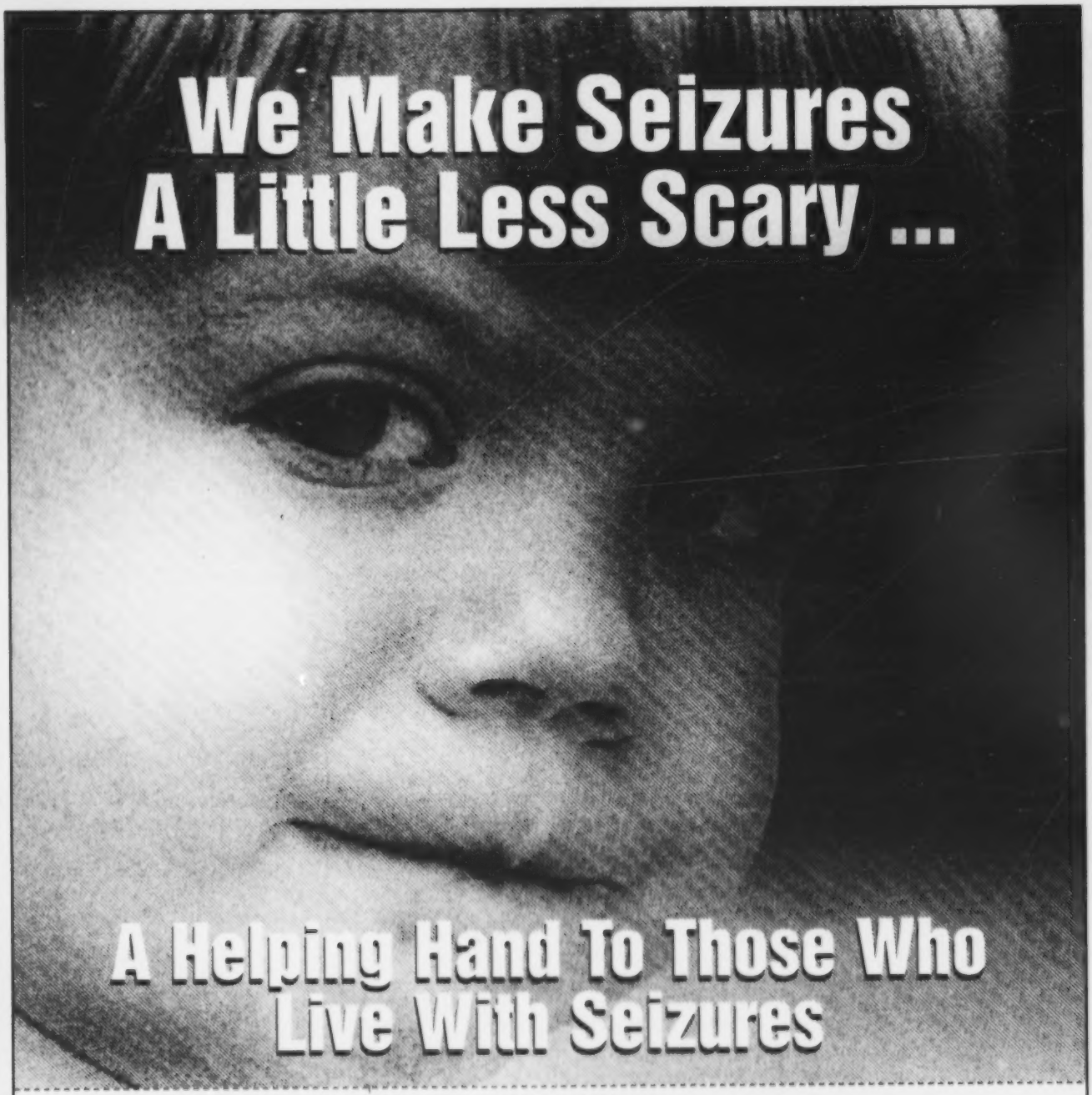

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Understanding Enuresis

The development of bladder control is a process that typically occurs over several years. Bladder control development varies quite normally in individual children. However, between one and two years, children usually become gradually aware of the sensation of a full bladder. By three years of age, most children are able to tense the muscles of the pelvic floor and "hold" urine for prolonged periods.

Our culture places much attention on how and when a child gains bladder and bowel control. It is not surprising, therefore, that family distress often results when this control does not occur. Daytime wetting (diurnal enuresis) and bedwetting (nocturnal enuresis) are quite common. "Enuresis" can be defined as the "involuntary discharge of urine by day or night (or both), in a child aged five years or older, in the absence of congenital or acquired defects of the nervous system or urinary tract." If a child has never been dry for a significant period, he or she is considered to have "primary enuresis." "Secondary enuresis" refers to loss of bladder control in a child who is at least four years old, after he or she has been dry for a significant period.

Nocturnal enuresis: Who is affected?

Nocturnal enuresis has been defined as ranging from one wet episode a month to seven or more a week. Based on an average of two wet nights per week, it is estimated that the number of children affected are: 15–20 percent of five-year-olds, seven percent of seven-year-olds, five percent of 10-year-olds, two to three percent of 12- to 14-year-olds and one to two percent of 15-year-olds. In older age groups, enuresis can be extremely stressful and socially disruptive. A person's ability to make changes in his or her life, such as starting college or getting married, is often inhibited by enuresis.

Contributing factors

A number of factors may contribute to enuresis. For example, genetic factors may play a role. A family history of enuresis is quite common, and one study found that identical twins were almost twice as likely as non-identical twins to both have nocturnal enuresis.

In children younger than five, delayed maturation may contribute to slower development of bladder control. A stressful life event can also contribute to the occurrence of enuresis. A small functional bladder capacity is often another contributing factor.

Constipation and sleep apnea are physical problems that may contribute to nocturnal enuresis. Chronic constipation can irritate the bladder, which results in frequent urination. Sleep apnea—periods of non-breathing during sleep—decreases oxygen levels. This may make a child less responsive to the sensation of a full bladder, and less likely to wake up when he or she needs to urinate.

The presence of a urinary tract infection (UTI) should be ruled out before beginning any treatment for enuresis. Approximately five percent of girls and two to three percent of boys will have a UTI at some point during childhood.

Dispelling myths

Enuresis can have a damaging effect on parent-child relationships and a child's relationships with peers. These damaged relationships may further lessen a child's self-esteem. This makes it especially important to dispel myths about the causes and prevention of enuresis.

Contrary to some misguided beliefs, bedwetting is not deliberate or controllable. Restricting fluids will not help a child develop bladder control. Shaming and rejecting the child does not stop bedwetting, but it does increase the child's anxiety and lower self-esteem.

Medication

Medication is one treatment option. According to the Enuresis Resource and Information Centre (United Kingdom), two main types of drugs are prescribed for bedwetting—antidiuretic hormone (ADH) and tricyclic antidepressants.

Studies have shown that some children who wet the bed produce less ADH than children who do not wet the bed. ADH is available by prescription in the form of Desmopressin, a nasal spray. This medication decreases the amount of urine output at night. Desmopressin has an almost immediate effect lasting five to nine hours, and has a success rate of approximately 70 percent.

Tricyclic antidepressants, such as imipramine (Tofranil), are thought to relax the bladder (detrussor) muscles, allowing the bladder to hold more fluid before contracting. Antidepressant drugs can take up to a week to take effect; possible side effects include irritability, loss of appetite, headaches and constipation. Like all medications, drugs given for enuresis should be stored safely out of the reach of children.

If your child has enuresis, your physician can tell you about the most recent medications available, and how they might be used in your child's case. It is important to remember that medications alleviate—rather than cure—nocturnal enuresis. Once medication is stopped, bedwetting often recurs. **EP**

This article was adapted from two articles previously published in THE INFORMER, *the newsletter of The Simon Foundation for Continence. For a free information packet, contact The Simon Foundation, P.O. Box 835, Wilmette, IL 60091; (800) 237-4666, (708) 864-9758 (fax).*

Enuresis: A Guide to the Treatment of Enuresis for Professionals is now available exclusively through the Simon Foundation for Continence. This guide is edited by Penny Dobson, R.N., executive director of the Enuresis Resource and Information Centre in England. The guide includes chapters on assessment, treatment methods, choosing a treatment program, dealing with relapse and advising the older child and adult. Although written for the professional, the readable style makes this book understandable and useful to the layperson as well. The book costs $24.95 and can be ordered directly from the Simon Foundation, P.O. Box 835, Wilmette, IL 60091.

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MOST PARENTS OF BED WETTERS THINK THERE IS VERY LITTLE THEY CAN DO TO HELP.

Some 3 million children, 10% of all kids between 5 and 10, wet the bed twice a week or more. If your child is in school, chances are at least two of his classmates are in the same leaky boat. No child should ever feel alone with this problem. But, of course, they do.

The good news: More is known than ever before that can help. Once, the only sure cure was time. 99.9% of our children leave this problem in the dust as they grow. And now there are some new ways to give time a hand.

THE BEST BEGINNING

For starters, pediatricians know a lot more about the causes of "enuresis" (that's the official medical name for it) than they used to.

Doctors today deal with this problem all the time. They have new techniques and sometimes medicines that can help manage bed-wetting, if not eliminate it altogether.

And now (finally!), there are pants you can buy that can make a real difference at your house, every night and every morning. Your child will still wet. He can't help it. But from now on, that doesn't have to mean he has to wet the bed.

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The makers of Pull-Ups® training pants have invented the first and only disposable underpants for larger children, 45 to 85+ pounds.

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THE WAY THINGS SHOULD BE

If yours is already a GoodNites family, there's some good news for you, too. GoodNites are now even more absorbent than before.

If GoodNites underpants are new to you, now is the time to try them. You will rejoice that you did.

GoodNites are not a miracle, but there's nothing like them. They help families keep bed-wetting in perspective. They help make dry mornings, in crisp clean sheets, routine. And make sleep-overs and other normal, healthy everyday kid things routine, too. The way they should be.

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GoodNites underpants were developed with the help of pediatricians and other childhood specialists. You'll find much of their good advice in these little booklets. One is written for parents. The other is for your child. For copies, please send $1 for postage and handling to: GoodNites Guides, P.O. Box 1165, Maple Plain, MN 55592.

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Food for Thought

Helping your child on a special diet eat right

by Marsha Magol

Persuading a child to eat different and nutritious foods, whether or not the child has special health care needs, can be an exhausting and frustrating experience. However, you can help your child develop positive attitudes about nutritious foods.

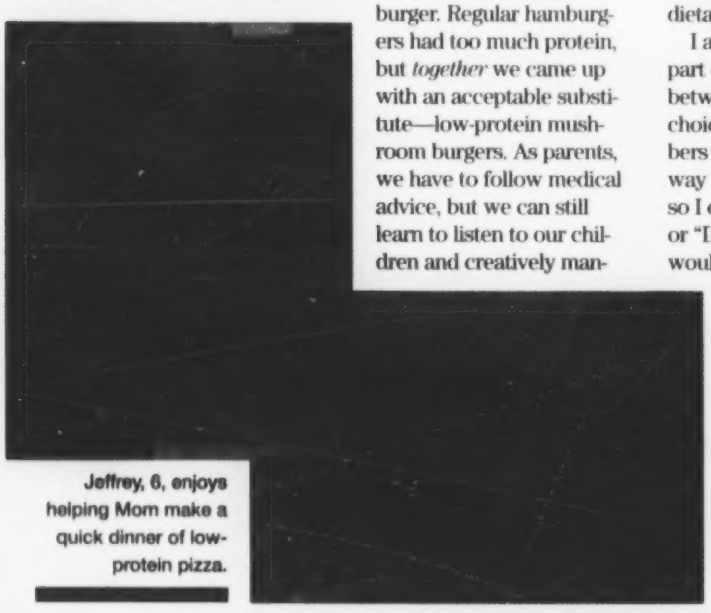
Children learn best by example. Remember, your child wants to be like you. If the child sees *you* eating more salads, fruits and vegetables, he or she may want to do the same.

Listening to our kids

My bright, six-year-old son, Jeffrey, has phenylketonuria (PKU), a metabolic disease that requires him to follow a low-protein diet regimen. This means plenty of substitutions when his friends may be eating "funner" food. When a special diet is a life-long requirement, it is important that children develop a sense of responsibility for what they eat. At the same time, it is important to allow them to express their feelings about the diet. We can learn a lot by listening carefully.

For example, Jeffrey recently said to me, "Mom, I really liked the 'peanut butter' (actually a low-protein substitute) and jelly sandwich you put in my lunch box today." I realized that this sandwich was more than just a tasty lunch. I knew that it also boosted Jeffrey's self-esteem to be able to eat food that looked similar to that of his peers.

Another time Jeffrey came home from school, sad and dragging, and said emphatically, "I don't like this diet!" Together, we figured out he was unhappy because he couldn't eat a hamburger. Regular hamburgers had too much protein, but *together* we came up with an acceptable substitute—low-protein mushroom burgers. As parents, we have to follow medical advice, but we can still learn to listen to our children and creatively manage their diets. Children appreciate being able to express their feelings openly and having their needs treated respectfully.



Jeffrey, 6, enjoys helping Mom make a quick dinner of low-protein pizza.

A voice and a choice

Parents can reinforce a sense of responsibility in children by giving them a voice and a choice in matters that affect them. Severely restricting your child without explanation can lead to immaturity and rebellion. Children will accept "rules" more readily when explanations are given. Although health conditions may limit some options, we can help children accept inevitable choices gracefully.

Parents can involve young children in food choices by talking about them. For example, a two-year-old can decide whether he wants a half glass of milk or a full glass. A four-year-old can be asked if he wants an apple or an orange, or whether he wants his bread toasted or plain.

Children can be deliberately presented with many situations in which they have to make choices and are given chances to succeed. We can creatively select the situations and let children make the choices. This sends a clear message that children are not just recipients of "orders," but participants in decisions that affect them.

For example, when Jeffrey was very young, I always kept frozen low-protein bread and pancakes in Ziploc bags in the freezer, on a low shelf at Jeffrey's eye level. I would let him choose between bread or a pancake by responding verbally, by pointing or by actually getting it out himself. This made him feel that he was "in charge," and was a very small step toward dietary self-management in the future.

I also kept a variety of fresh fruit and vegetables in the lower part of the refrigerator so Jeffrey could see the choices between tangerines, grapes, plums and other fruits, or the choices between lettuce, carrots, celery, tomatoes or cucumbers in the vegetable crisper. The pantry was set up the same way with small cans of fruits and vegetables on the lower shelf so I could ask Jeffrey, "Do you want carrots or green beans?" or "Do you want Mott's peaches or a Strawberry Fruit Pak?" He would go to the drawer where the measuring cups are kept and hold a cup up to the item he wanted.

Introducing new foods may take some effort. However, you will be rewarded quickly when you see your young child making the right choices from a smorgasbord of food. You can help your child develop tastes and preferences that last a lifetime. **EP**

This article was adapted from two pieces by Marsha Magol that first appeared in National PKU News. *Marsha is a regular contributor to this publication. She and her husband have one son, Jeffrey, 6. They live in Tampa, Florida, where Marsha works for GTE.*

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Irene Pollin, author of TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS, *is a parent and psychiatric social worker. In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope with long-term effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed. After the loss of two of her own children, Pollin returned to school for training as a psychiatric social worker.*

Although TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS *was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members. For example, this excerpt, which discusses the doctor-patient relationship, can also be applied to the doctor-parent relationship.* TAKING CHARGE *is available from Exceptional Parent Library (800/535-1910).*

Forging an Effective Doctor-Patient Partnership

Forging effective doctor-patient partnerships may be one of the most important "take charge" tools at your disposal... Your relationship with your physician will affect your emotional and personal well-being, not just your physical condition. Your level of stress will decrease if you trust, respect and feel comfortable with your physician, if you believe that he cares about you and will be responsive to you. Indeed, your interactions with your doctor will influence the quality of your daily activities and can affect life-and-death decisions...

You can create supportive relationships with your physicians. When you establish the boundaries of your partnership early on, your doctor will be concerned with your feelings, not just your physical condition. That's important because your emotional comfort level with your doctor can affect how you respond to prescribed treatments. But first you must understand how your chronic condition differs from other medical problems you might have encountered in the past, and how your care will diverge too...

Your first encounters with the specialist may be marked by frustration. For example, she may be unable to reach a clear diagnosis or may accurately analyze the problem only after exhaustive tests. Indeed, the waiting period between your first appointment with the specialist and a definitive diagnosis may seem like a special kind of purgatory. Your anxiety will most likely heighten as you undergo physically unpleasant or even risky tests. You may exhaust yourself from the constant worrying but still have to pay the mounting bills and fill out endless insurance forms.

Finally, your doctor will arrive at a definitive diagnosis. You may feel somewhat relieved that you now have something concrete to deal with, but the news isn't all that good. The specialist, for example, may have few options to offer as treatments. She may also explain that TAKING you will experience only an incomplete recovery; the progress of your disease may be unpredictable and unsure... The only certainty is that it cannot be cured.

Despite the unwelcome news, you need not feel helpless with your physician or your illness. One of the best ways to take charge of your disease is to know exactly what you're dealing with. Unless you know what your disease is, how it manifests itself, its likely prognosis and how the treatments may or may not help you, you cannot make a realistic evaluation of your medical condition or the course of action you should pursue. Indeed, unless you are fully informed, you cannot be responsible and in control of your medical decisions. That means asking the specialist the right questions...

- Are you sure of the diagnosis?
- How did I get this disease?
- What factors make it worse or better?
- How long must I stay in the hospital?
- What should I expect as far as disabilities? Will the disease get worse?
- Can the symptoms be controlled?
- What treatments are available?
- Is the treatment you're recommending the latest?
- What is its success rate?
- What are the risks of this treatment?
- Do the benefits outweigh the risks?
- Are there any experimental treatments I should know about?
- If I take this medication for many years, what are the potential side effects?
- If I have surgery, will it stop the disease or will the process continue?
- What should I be doing to take care of myself?
- What would make me feel better?
- What would make me feel worse?
- Is there anything I can do to slow the disease's progress?
- Will I have to limit my home activities and life-style?
- What kind of emotional reactions can I expect?
- What can I expect for the future?

...You may also wish to bring your spouse, a close relative, or friend along to ask questions that might have eluded you. Take notes (or ask your friend to take notes) during this important visit. The doctor may impart too much information for you to absorb all at once in your state of anxiety, and you'll want an extra pair of ears to help you hear and record everything...

Finally, it's important for you *not* to feel stupid, intimidated or fearful. Your doctor needs you to comply with the treatments she recommends, and that's best accomplished if you understand what she wants you to do and why.

Reprinted with permission of Times Books, a division of Random House, Inc., from TAKING CHARGE, *© 1994 by Irene Pollin.*

UNCOMMON FATHERS: REFLECTIONS ON RAISING A CHILD WITH A DISABILITY is a collection of essays written by fathers of children with disabilities. This diverse group of dads—including students, artists, teachers, a Christian missionary, a retired police officer, businessmen, attorneys and a rabbi—have children ranging in age from four to 28, with a variety of disabilities. UNCOMMON FATHERS, edited by Donald J. Meyer and published by Woodbine House, is available through Exceptional Parent Library, (800) 535-1910. 206 pp; $14.95 (paperback).

The following is an excerpt from "He Canters When He Can" by Greg Palmer:

When Ned was four he began exhibiting some classic autistic behavior, which I'm told is rare for a child with Down syndrome. He would go off into a corner for hours and babble incoherently to himself, while slowly, rhythmically rocking his body. We were concerned, of course, but not unduly. Otherwise Ned was a very happy, outgoing boy who was making good intellectual and physical progress. He especially liked phonograph records and television, and would listen to and watch the same material over and over again. His ability to entertain himself for hours, whether by record, videotape or his own internal, unintelligible monologues, was often a relief for us—a respite from the intense attention he otherwise needed.

A few years after the monologues began, he was rocking and talking one Sunday afternoon while I sat reading the paper, not paying any attention to the meaningless recitation going on nearby. And I suddenly heard him say, clearly, precisely and with feeling, "You're a very bad man. No, I'm a very good man, I'm just a very bad wizard." He was reciting *The Wizard of Oz*…

I soon learned he had memorized all of *Snow White*, too, as well as *Puss In Boots*, most of the television episodes of Jim Henson's *Muppet Babies* and the songs on a dozen different recordings by Raffi, Fred Penner, Rosenschontz and others. It occurred to me that Ned had never been babbling incoherently, that all those years he was entertaining himself with the material he liked. I had underestimated him badly, and I've tried never to do that again…

I remember sitting on my front porch that September evening when we first learned that Ned had Down syndrome, and suddenly having the chilling realization that, not for as long as *we* lived but for as long as *he* lived, Ned would be our responsibility; not the state's, not his relatives', especially not his brother's. We could hope that some day Ned would be self-sufficient, and work as hard as possible with him towards that goal. We could trust that his older brother would take care of him in their adulthood, not because he had to, but because he wanted to. But we still had to be prepared for the physical, financial, emotional alternative—parental custody, even from beyond the grave. Loving Ned with all our hearts would never be enough.

That preparation, both of Ned and his world to be, has taken planning, patience and research, including knowing what opportunities are available within the community. Ned was three weeks old when he went to his first infant stimulation class… That was just the beginning of a quest for good schools, camps and experiences, a quest that will never end.

Even so, I've found the essence of raising a special child is not in the grand questions…, but the more immediate question of "What did you do with my watch?" While not losing sight of the big picture, it is the daily business of life, the million things we do at home with and for Ned, that seem to have the most beneficial effect on him, and us.

Just one example. I can't recall a time when Cathy or I haven't read to him in the evening right before he goes to bed… His current interest is biographies—Jefferson, Washington, Lincoln and especially Martin Luther King Jr. For 10 Halloweens in a row, Ned was the same witch, but this past year he finally wanted to be someone else. He wanted to be the Reverend Dr. King, as a tribute to a man he's read about and admires. It was a wonderful idea and we were proud of him, even if we didn't have the slightest idea how we were going to turn this little white kid into his hero without offending half the neighborhood, makeup-wise. (We decided on just a dark suit and glasses. To me, Ned looked more like Roy Orbison than Martin Luther King, but he was satisfied.) As his father, I know the memory of this past Halloween and the Martin Luther King Dilemma will eventually overwhelm any memories of a decade of trying to talk a very stubborn little boy out of that ratty witch costume.

I'm making Ned sound like the perfect kid, a constant delight to everyone all the time. That is not my intention, and not the case… Somebody must say it. Developmentally disabled children can be a real pain in the butt, and there is no guilt in a parent admitting that…

For all his occasional obstinacy, though, the hardest thing about being Ned's father is contemplating the future. I want no more and no less than for Ned to be happy every day of his life. But I judge happiness on my terms, from my experience. Happiness for me is being married for 26 years to a woman I love, and having children I love as well. Happiness is having good and talented friends, interesting work to do and the freedom to stop doing it for a while and just go somewhere. And Ned may never have any of these things…

The principal disadvantage of my decision always to deal with Ned's situation logically and realistically is that I can't shake it, even when I want to fantasize about a glorious future for him.

But that's a lot different than giving up. Only my own narrowness of vision makes me think that when Ned is 46, his idea of happiness will be what mine is now. And if there is some overlap, I know his mother and I have done all we can to get him ready…

He will be a very good man, and maybe a very good wizard.

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HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Conversion Rights

Q We live in Georgia. In 1987, our daughter was born with severe mental retardation. At the time, we had health insurance coverage as individuals in a group policy. Our policy was later transferred to another insurance company.

That insurance company terminated the policy in 1989. In order to continue health insurance for my daughter, who is considered "uninsurable," my husband and daughter continued health insurance on a conversion policy.

In the fall of 1994, our policy was again transferred to another insurance company. In April, we received a letter saying that this insurance company was terminating the policy. They say we can apply for coverage with another insurance company under our conversion rights.

How can they do this? What protection do we have against this happening over and over again?

A Since the federal government has not yet passed a health care reform act, the degree of consumer protection in regard to health insurance depends largely on state law. And that, of course, differs dramatically from state to state.

Some states, for example, have passed health insurance reform acts that guarantee important protections for consumers. In several of those states, the legislature has authorized the establishment of a series of standardized health insurance plans. Each plan has specific limits and exclusions; each plan provides a different level of benefits and a different deductible. Most importantly, however, these standardized health insurance plans are usually available to all applicants, regardless of their health status. This makes children and adults with disabilities eligible for health insurance coverage in these states.

In addition, these standardized plans are usually "community-rated." Community rating means that a company has to charge the same price to each applicant for the same health insurance benefits, regardless of the applicant's health status.

Georgia, however, has not yet passed a health care reform act, and does not currently offer either a community-rating system or a guarantee of eligibility for health insurance coverage. However, existing state insurance regulations may relate to your concerns.

The first step would be to discuss your situation and the existing regulations with the Georgia State Insurance Department's Consumer Services Section (716 West Tower, 3 MLK Jr Dr., Atlanta, GA 30334; 404/656-2070; 404/657-8542, fax).

You can ask specifically about state regulations in regard to termination of health insurance coverage by an insurance company, and about conversion rights. Conversion rights generally allow for a continuation of health insurance coverage under certain conditions, albeit under a new framework. If a group insurance plan that includes conversion rights is canceled, for example, it may be possible for consumers who were covered by that plan to continue benefits by converting to an individual policy.

State regulations may specify the conditions under which a health insurance company can terminate an insurance policy. In addition, there may be regulations requiring that coverage be continued under conversion rights when an insurance policy is terminated by a company, and that also require the new policy to include benefits similar to the original policy.

You may also want to review the health insurance plan offered by The Arc, The Arc Group Major Medical Insurance Plan. The plan is available to Arc members and their families. It was designed specifically to meet the needs of children and adults with mental retardation and other disabilities.

Although there's no guarantee of acceptance, the insurability of each applicant is individually evaluated. At this point, children must be at least 10 years old to be covered by the Arc health insurance plan. However, since your daughter will be 10 in another year and a half, the Arc plan may provide an eventual solution.

At present, the plan is not available to residents of New Jersey, New Hampshire, Vermont or Connecticut, apparently because of conflicts with the insurance regulations of those states. However, it is currently available to residents of Georgia. For information about the Arc, call (800) 433-5255, voice, or (817) 277-0553, TTY. For detailed information about The Arc's insurance plan, contact the Arc's insurance administrator, The Albert H. Wohlers Company (1440 N. Northwest Highway, Park Ridge, IL 60068-1400; 800/323-2106).

I think it is also important to write to your legislative representatives—on both the state and federal level—about this issue. On the state level, you may wish to suggest that the legislature consider enacting a health insurance reform act that would provide important protections for children and adults with disabilities.

On the federal level, Congress is now beginning to debate health care and health insurance issues once again. I think it is essential that legislators at this level become more fully aware of the health insurance coverage difficulties now faced by families of children with disabilities. **EP**

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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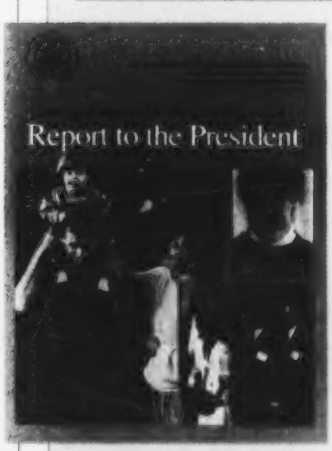
WHAT'S HAPPENING

No Place Like Home

An excerpt from the annual report of the President's Committee on Mental Retardation

The President's Committee on Mental Retardation (PCMR) has released its 1994 annual report entitled THE NATIONAL REFORM AGENDA AND CITIZENS WITH MENTAL RETARDATION: A JOURNEY OF RENEWAL FOR ALL AMERICANS. The report, authored by Dr. Glenn Fujiura of the University of Illinois at Chicago, reflects the contributions of a number of self-advocates, parents, family members and professionals. It includes recommendations made within the context of welfare and health care reform.

Illustrating these recommendations are the stories of several individuals with mental retardation. The following is a excerpt from the section of the report entitled "Home."



...People with mental retardation can and do own and rent their own homes all through the U.S. Though little used to date, this is the most rapidly growing type of residential option. In localities across the nation, innovative funding options are being implemented. State governments, including Colorado, Connecticut, Florida, Illinois, New Hampshire, Michigan, New York, Rhode Island and Vermont, have developed innovative financial assistance programs for cash assistance, leases, rent subsidies and vouchers.

David Guillet just purchased a condominium in Cumberland, Rhode Island. Formerly a resident of group homes, he, together with his parents, Marge and Lou, were pioneers in the development of home ownership options in their state. Through a collaborative effort of state agencies, they obtained a low-interest mortgage and a grant for the down payment, closing costs, and furniture. Compared to publicly-funded group homes that often come with unneeded service packages and associated staffing expenses, home ownership may be less expensive.

"My son has very severe disabilities," said Mrs. Guillet, "quadriplegic, legally blind, with severe seizures. Yet, I have the same fears for David as I do for my other children, who do not have disabilities. We are helping David expand his relationships by introducing David to the fire department, to his immediate neighbors, by holding an open house. The neighbors were wary, assuming the state had purchased the condo. Their perceptions immediately changed when they found out that David was the owner, not some "ward" of the state.

"We have choices now. We pick the support staff. David has complete control of the choices in his life. David can eat what he wants to eat, when he wants to eat. If he wants to wear a blue shirt with green shorts, that's OK. I can see the difference in his eyes."

The great challenge is to see beyond current service paradigms. Many people with mental retardation who receive residential services live in housing where services and personal assistance are based on group considerations and agency preferences rather than individual needs and choices. People with mental retardation are often wrongly viewed by government agencies and service providers as needing "special housing," rather than as individuals with idiosyncratic needs for support...

To obtain a free copy of THE NATIONAL REFORM AGENDA AND CITIZENS WITH MENTAL RETARDATION: A JOURNEY OF RENEWAL FOR ALL AMERICANS, contact PCMR, 330 Independence Ave., SW, Wilbur-Cohen Building 5325, Washington, DC 20201; (202) 619-0634.

Publications

• *Nutrition Care for Children with Prader-Willi Syndrome ages 3-9* is a 12-page booklet that addresses calorie needs, supplements, diet planning and food management, and explains food-exchange lists. Booklets are $5 each and can be purchased from the Prader-Willi Syndrome Association, 2510 S. Brentwood Blvd., Ste. 220, St. Louis, MO 63144; (800) 926-4797.

• *Medical Facts About Spina Bifida*, produced by the Kennedy Krieger Institute in collaboration with the Spina Bifida Association of America, is a comprehensive information resource for parents of children with spina bifida. Individual copies of the 12-page booklet cost $4. Contact the Spina Bifida Center, Kennedy Krieger Institute, 707 N. Broadway, Baltimore, MD 21205; (800) 873-3377 or (410) 550-9000.

• *Living SMArt* is a bimonthly newsletter written by adults with spinal muscular atrophy (SMA). The newsletter features information, networking and support for adults with SMA, as well as parents. Yearly subscriptions cost $6; additional donations are welcome. For a complimentary issue, contact Living SMArt, c/o June Price, editor, 3576 S. 43 St., #32, Milwaukee, WI 53220-1550; (414) 541-2848; e-mail: LivngSMArt@aol.com.

• The *1995 Resource for People with Facial Difference* is a comprehensive directory containing listings of organizations for people with facial difference, their families and professionals. The directory also provides information on relevant publications, videotapes and audio cassettes. To receive a complimentary copy of this publication, send a self-addressed 9 x 12 envelope with $3 postage to Let's Face It, Box 711, Concord, MA 01742-0711.

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Education Department Submits Proposal to Reauthorize IDEA

On June 30, 1995, the U.S. Department of Education submitted to Congress a proposal to revise and reauthorize the Individuals with Disabilities Education Act (IDEA). The proposal reflects comments from over 3,000 parents and educators. It marks the first substantial revision to the legislation since Congress enacted PL 94-142, the basis of the IDEA, in 1975.

The department based its proposal on six principles: (1) connect the IDEA with state and local education improvement efforts so students with disabilities can benefit from them; (2) improve educational results for students with disabilities through higher expectations and meaningful access to the general curriculum, to the maximum extent appropriate; (3) address individual needs in the least restrictive environment for the student; (4) provide families and teachers—those closest to students—with the knowledge and training to support students' learning; (5) focus on teaching and learning and (6) strengthen early intervention to help ensure that every child starts school ready to learn.

The proposed changes include:

- Increasing parental involvement by requiring schools to issue regular reports to parents on their children's progress, and by including parents in decisions about their children's placement.
- Providing parents and teachers with better training on helping students with disabilities achieve in school. A national network of parent training centers would be expanded. A professional development program would be expanded to help all teachers work more effectively with students with disabilities.
- Providing parents in every state the option of resolving disputes with schools over their children's education through mediation.
- Helping schools maintain safe and disciplined classrooms by allowing schools to move a student who has brought a firearm or other dangerous weapon to school to an alternative educational setting for up to 45 days.
- Improving school safety by permitting hearing officers to authorize the temporary removal to an alternative setting of a student who is substantially likely to injure himself or others.
- Promoting high expectations and achievement by focusing the individualized education program (IEP) on measurable annual objectives and achievement in the general curriculum, whenever possible, and by including the student's regular teacher in developing the IEP.
- Ensuring accountability for educational results by requiring greater participation of students with disabilities in state and district assessments, and by asking each state to establish goals for the performance of children with disabilities.
- Revising the formula for grants to states so that new dollars would be distributed based on the state's population, rather than on the number of children with disabilities being served. Current law tends to encourage over-identification of children—particularly minority children—as having disabilities. Current law also discourages states from doing early intervention and pre-referral activities.

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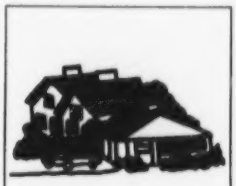

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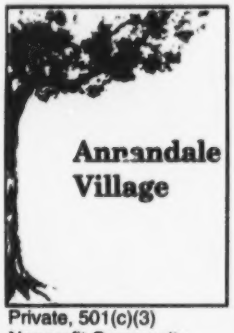

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Jason and Nordic Publishers,
PO Box 441,
Hollidaysburg, PA 16648.
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Woodbine House,
6510 Bells Mill Road,
Bethesda, MD 20817,
(800) 843-7323

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Networking

Information from The National Parent Network on Disabilities

The National Parent Network on Disabilities Board of Directors

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Patricia McGill Smith
Executive Director

We've moved!

Our new address is:
National Parent Network on Disabilities
1727 King Street, Suite 305
Alexandria, VA 22314
Phone: 703-684-6763
Fax: 703-836-1232

Welcome to the World

The Americans with Disabilities Act (ADA), passed in 1990, has now existed for five years! This anniversary provides me with a chance to reflect on what the ADA will mean for children born with disabilities in 1995.

Children born in the last ten years, thankfully, may not have experienced rejection and hostility because of their disabilities; I hope they haven't. Although our country was founded on the premise of hospitality—our forefathers sat together with the Native Americans to celebrate the first Thanksgiving—the United States also has a great deal of hostility threaded throughout its history. Often there has been no "welcome mat" for people of different nationalities or races, or even for people with different ideas. Similarly, discrimination towards people with disabilities has a disturbing past, one full of injustices. The ADA is and will be the "welcome mat" for children with disabilities today and in the future.

This is the message of the ADA to young children growing up with disabilities:

"You are welcome here—the corner curbs are cut for your chair… hearing devices are available at the concert… there is a space for your wheelchair at the movie theater… the grocery store has an extender to reach high shelves… McDonald's has picture menus… and the door handle and the light switch at Mom's office are set at a reachable level. You can go to school, participate in after-school activities, enter the gymnasium and attend school dances.

"When you go to college, you'll find new freedom. You'll have an accessible campus, devices in each room to signal fire, accommodations to help with learning disabilities. But most of all, when you grow up and need a job, you'll find transportation to get you to work and accommodations to help you succeed in working. Local buses will pick you up. If you need to attend a business meeting in another city, you'll be able to fly there. You'll find accommodations to make working a probability and a reality. The ADA has opened these doors for you."

Do I have fears about ongoing hostility and further discrimination toward children with disabilities and their families? Yes. My fear is that young people and their parents may forget. If you don't remember the difficult past, you might become complacent and take things for granted. You might not realize how fragile our collective "freedom" is. You might forget the recent times when children with disabilities were denied entrance into schools and couldn't maneuver through society because they were not welcomed into it. In those times, they were viewed as a tragedy, sent away from home, set apart. They certainly were not accepted as important, contributing members of the community.

Changing the environment in this country from hostile to hospitable is the great gift of the Americans with Disabilities Act. Welcome to the world!

—Patricia McGill Smith

As EXCEPTIONAL PARENT *was going to press, planning was underway for a celebration in Washington DC in honor of the fifth anniversary of the ADA. The event, "Voices of Freedom: America Speaks Out on ADA," was scheduled to take place on July 26, 1995.*

"Promises to Keep" Rally an Unparalleled Success

On June 22, the National Parent Network on Disabilities—in cooperation with the Spina Bifida Association of America, the Bazelon Center on Mental Health, the Epilepsy Foundation of America, the National Association of Medical Equipment Suppliers, Justice for All and the Consortium for Citizens with Disabilities—staged a rally for the rights of people with disabilities on the west steps of the U.S. Capitol. More than 1,500 people from all over the country attended and made their voices heard.

The rally focused on the issues of preserving the Americans with Disabilities Act (ADA), maintaining the protections and funding of the Individuals with Disabilities Education Act (IDEA), maintaining funding for Medicaid and Medicare and protecting the children's Supplemental Secu-

continued on page 64

Senator Bill Frist, R-TN, asked for help in placing "the rights of people with disabilities above partisan politics." He was joined on stage by Patricia McGill Smith, Becky Ogle, government affairs representative of the National Association of Medical Equipment Suppliers, and a young advocate of the future.

BEST COPY AVAILABLE

Senator John Chaffee, R-RI, emphasized the need to protect cash payments to children with disabilities who receive SSI—"Doesn't it make sense to keep people at home rather than in institutions?" On stage with Senator Chaffee was Patricia McGill Smith, NPND executive director.

continued from page 63

rity Income (SSI) Benefit Program.

Members of Congress expressed their support for the disabilities rights movement, and many of them voiced concern that the rights we have fought so hard to gain could be destroyed by the end of this session of Congress. Speakers included Senator John H. Chaffee, R-RI; Senator Bill Frist, R-TN; Senator Tom Harkin, D-IA; Senator Paul Wellstone, D-MN; Representative George Miller, D-CA; Representative William Goodling, R-PA; and Representative Sheila Jackson Lee, D-TX.

Paul Marchand, director of the Arc Government Affairs Office, opened the rally with a welcome from the Consortium for Citizens with Disabilities and read a letter from Tony Coelho, chairman of the President's Committee on Employment of People with Disabilities, who could not attend. Gene Mitchener, an inspirational speaker from Los Angeles, urged the people in the crowd to speak for themselves. Justin Dart, a long-time advocate in the area of disability policy, closed the rally, speaking eloquently about the need to preserve the rights of people with disabilities.

Following the rally, participants called on their legislators. Parents, self-advocates and professionals hit the halls of Congress to spread the word. And although we were competing with the activities relating to the nomination of Dr. Vincent Foster for U.S. Surgeon General, it seemed clear on June 22, that Congress got the word! Now we must beat the drums and raise up a wall of parents the likes of which has never been seen. *If not now, when? If not us, who?*

Now available!

The "Promises to Keep" rally is available on videotape. This video is an excellent tool with which to open talks with parents and other advocates about the need to be involved in the legislative process. For a copy of the videotape, please send cash, check, money order and/or purchase order for $33.95 (includes postage) to Inclusion Incorporated, 1436 Independence Ave. SE, Washington, DC 20003-1536; (202) 546-4464, (202) 546-4465 (fax), Internet: Inclusion@aol.com.

Women and Disability

The International League of Societies for Persons with Mental Handicap (ILSMH) has recently initiated a four-year comprehensive program effort on behalf of women. The ILSMH has established an Action Group on Women and Disabilities, directed by Patricia McGill Smith, NPND executive director. The Action Group is developing positions and recommendations regarding women who have cognitive disabilities and their caregivers. In September, at the International Women's Conference in Beijing, Patricia McGill Smith will represent ILSMH by speaking on "Women Who Care, A Review of Gender, Disabilities and Family Life for Caregivers of People with Mental Disabilities." She has conducted a survey to gather the ideas, beliefs and experiences of women who care for those with disabilities, and welcomes any additional responses.

Mark Your Calendars!

For more information, contact Gail Johnson, National Parent Network on Disabilities, 1727 King Street, Suite 305, Alexandria, VA 22314, (703) 684-6763

The NPND 1995 Annual Conference

"We Have Promises To Keep"

September 30-October 2, 1995
St. James Hotel
950 Twenty-fourth Street, NW
Washington, D.C. 20037

Honoring:

Dr. Gunner Dybwad
Professor Emeritus
of Human Development,
Brandeis University, Waltham, Mass.

& The NPND Keynote Speaker

Gene Mitchener
Motivational speaker and humorist

New PTIs

The following is a list of new Parent Training and Information Centers (PTIs). This list includes both new facilities and new branches of already-existing PTIs. Many of these new branches have been created to serve underrepresented and underserved parents and families, as evident by their organization names.

Family TIES (Training, Information, Education, Support) Network
1240 S Main St, Apt 117F
Morton, IL 61550
(309) 266-9597
(309) 263-3578 (fax)

National Center for Latinos with Disabilities (IL Chapter)
1921 S Blue Island Ave
Chicago, IL 60608
(312) 666-3393
(312) 666-1788 (TTY)
(312) 666-1787 (fax)

AWARE (Assisting With Appropriate Rights And Education)
200 N Vineyard Blvd, Ste 310
Honolulu, HI 96817
(808) 536-2280

Northern Manhattan Parent Training and Information Center
120 W 105 St, #L1
New York, NY 10025
(212) 666-1300
(212) 749-5021 (fax)

Project Empower
PO Box 851
Greenville, MS 38702
(601) 366-5707

MPACT (Missouri Parents Act)
3100 Main St, Ste 303
Kansas City, MO 64111
(816) 531-7070

COPE (Creating Opportunities for Parent Empowerment)
810 Potomac Ave SE, 1st Fl R
Washington, DC 20003
(202) 543-6482

Pathfinder Family Center
Arrowhead Shopping Center
16th & 2nd Ave SW
Minot, ND 58701
(701) 852-9426
(701) 852-9436 (TTY)

Rhode Island Parent Information Network
500 Prospect Street
Pawtucket, RI 02860
(401) 727-4144

Parents Active for Vision Education
4970 Arville
Las Vegas, NV 89118
(702) 253-1939

729

NEW PRODUCTS

CHILDFINDER

ChildFinder can help parents locate children when they have become separated from one another. The rechargeable battery-operated system, which works in most indoor and outdoor settings, includes one or two wireless transmitters to be worn by the child(ren) and a receiver for the parent. When a child wanders beyond the pre-set range (adjustable from a few feet to more than 1,000 feet), warning signals are emitted and a colored LED display pinpoints the child's location. The child's transmitter features a panic alarm that allows the child to transmit a signal to the parent with a touch of a button.

Gavrity Electronics, Highland Park, NJ 08904

Circle # 195

DESTINATION: RAIN FOREST

Destination: Rain Forest is an interactive CD-ROM that combines learning about the South American rain forest with activities encouraging vocabulary development, reading and writing. Users can create interactive electronic books; color or black-and-white printed artwork; poetry; on-screen puppet plays and theater productions; journals, diaries and letters; research reports and multimedia presentations. Users select from a variety of backgrounds, on which they place "stickers" illustrating people, plants and animals. They can incorporate music, spoken dialogue and animation to create their own adventures. The program is available in both Windows and Macintosh versions and is TouchWindow-compatible.

Edmark Corporation, Redmond, WA 98073-3218

Circle # 196

DESKCASE

With its wide base and tapered top, the DeskCase provides a stable, sturdy working environment that can accommodate a wheelchair. The unit includes two adjustable shelves and a writing desk with torso cut-out for easy access. It is available in a natural wood finish, or Formica with a choice of up to three colors. Optional accessories include a wide desk-side shelf for a computer monitor, and a holding/support bar.

Kids in Mind by Goshen Enterprises, Fair Lawn, NJ 07410

Circle # 197

BABY'S BOOK NOOK & NEO NOOK

Baby's Book Nook is a clear acrylic three-part frame designed to hold drawings, photographs and illustrated children's books. It is intended to encourage curiosity, visual stimulation and development of early physical skills—reaching toward the pictures, looking from side to side, lifting the head and bearing weight on the arms. This product is also suitable for use with older children with disabilities. The Neo Nook is a smaller version that fits in a bassinet and is suitable for use with infants weighing up to 12 pounds. Both models include three black-and-white visual stimulation cards.

The Baby Look Company, Grand Rapids, MI 49503

Circle # 198

WEAR•EVER

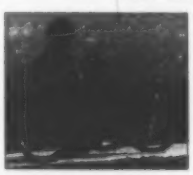
WEAR•EVER incontinence underwear is designed to provide better protection than disposable alternatives. Made of Hypersorb fabric, these lightweight undergarments pull urine away from the skin, dry quickly and can be washed up to 200 times without losing absorbency. Waterproof liners protect outer clothing. Children's styles—available in small, medium, and large sizes, for boys or girls—come in a choice of eight- or 15-ounce capacities. The pull-on style is also available in extra-large.

TMI Healthcare Products, Inc., Rougemont, NC 27572

Circle # 199

TOP END LI'L EXCELERATOR

Designed especially for young riders, the TOP END Li'l Excelerator is a lightweight, hand-crank cycle for children who cannot pedal using leg power. Available in 12- and 14-inch widths and heights, this three-wheeled cycle features an adjustable seat with a two-inch cushion, a smooth three-speed shifter in an easy-to-reach position, 20-inch performance wheels with knobby tires and adjustable dual footrests with safety straps. A parking brake is standard. Optional accessories include horizontal handles, seat restraints and custom colors.



TOP END by Action, Pinellas Park, FL 34665

Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT'S "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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Since 1971

Library

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MARK RUSSELL
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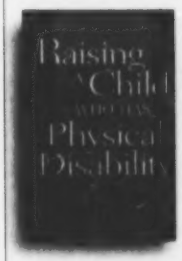

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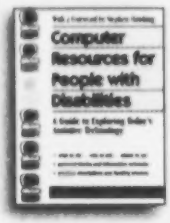

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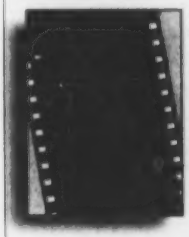

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EDITED BY M. MACE
Shows hundreds of products along with names, addresses and phone numbers providing customers with the information to make the best decision.
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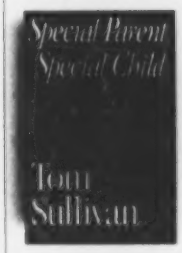

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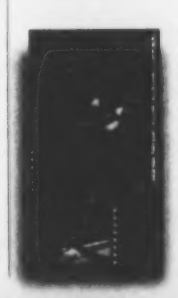

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This video presents a unique developmental approach to supporting the child in learning independence in the management of "bathroom" skills.
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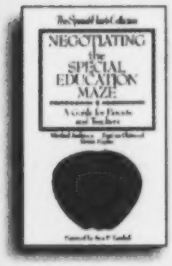

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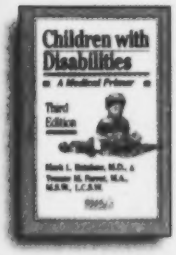

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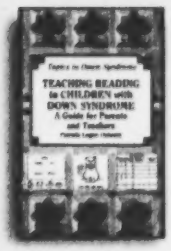
For parents and professionals. Over 200 detailed illustrations, an extensive glossary, and a section on syndromes.
PB0710D **$29.00**

DOWN SYNDROME



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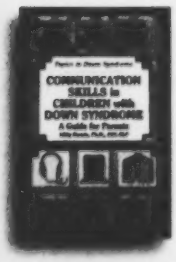

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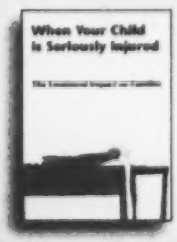

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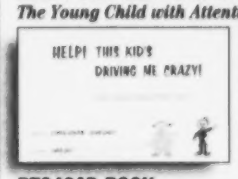

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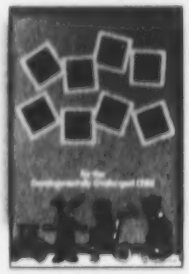

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Of five-year-old Blair, big sister Caitlin says, "I'm proud she is my little sister!"

I'M PROUD OF MY SISTER

by Caitlin Crossman

My sister, Blair, is a twin. Her twin sister is Taylor. Blair has cerebral palsy. When she was a baby, she couldn't pronounce words. Last March, Blair had surgery, and I felt sad. Blair has braces and a wheelchair and a walker.

When we go out, people come up to me and ask me what is wrong with her. I say, "Blair has CP, but she is still a part of my family and I love her very much."

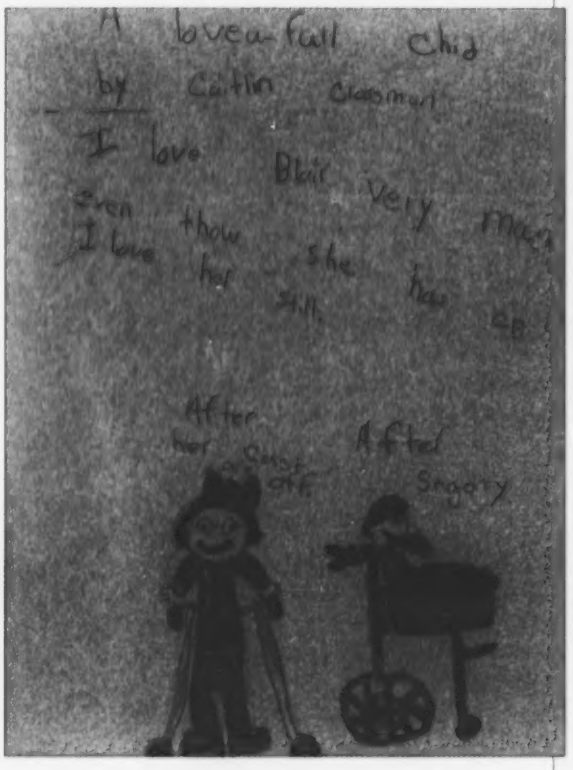
I am happy I am Blair's big sister, and I am proud she is my little sister! EP

(From left) Taylor, Caitlin and Blair paused for a photo in front of the Christmas tree on their way to a holiday concert in December 1994.

Caitlin Crossman, 7, lives in Haymarket, Virginia. In September, Caitlin will be a second grader at Mountain View Elementary School. Her hobbies include gymnastics, horseback riding, drawing and writing.

Twins Blair and Taylor, 6, will also be attending Mountain View Elementary in September; Blair will join an inclusive kindergarten class, and Taylor will be a first grader.

Wearing their shades, the Crossman girls, (from left) Caitlin, Taylor and Blair, enjoy a day at the beach during a 1993 family vacation at Nags Head, North Carolina.



The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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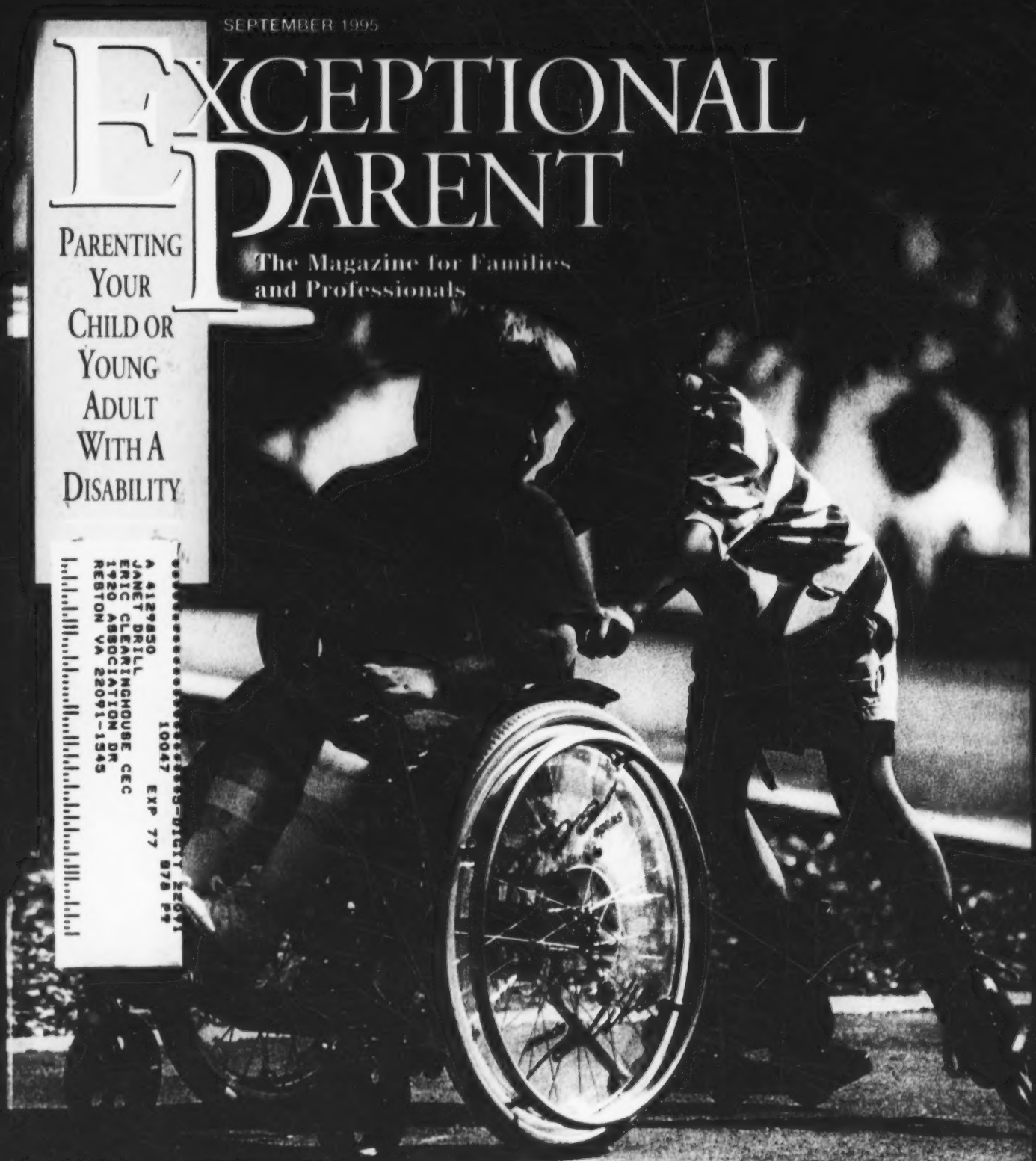
SEPTEMBER 1995

EXCEPTIONAL PARENT

The Magazine for Families and Professionals

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY



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23rd Annual Education Issue

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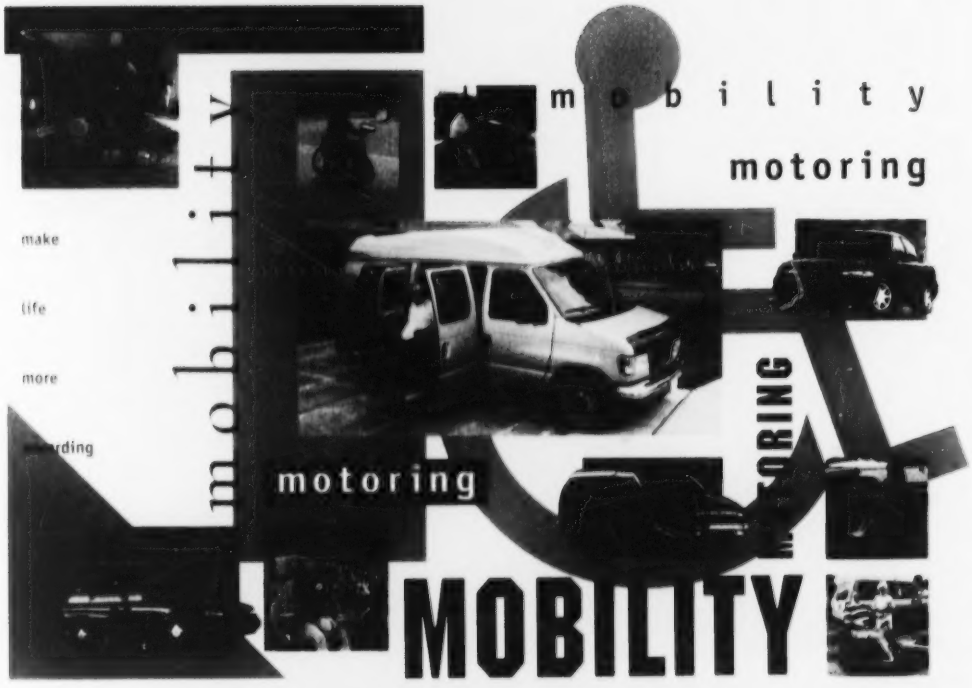

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[2] *Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance Plan. Vehicles covered by the Lincoln Commitment, F-Series Preferred Care or Red Carpet Lease plans have additional benefits.*

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EXCEPTIONAL PARENT

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971

The Magazine for Families and Professionals

AUGUST 1995 VOL. 25, ISSUE 8

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COVER: Back-to-school time is time for new friends. Photo courtesy of The MED Group, 3223 South Loop, Ste. 600, Lubbock, TX 79423; (800) 477-6272; (806) 793-6480, fax.

BPA INTERNATIONAL

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EDITOR'S DESK

Choices, Quality, Respect

Educating children is a challenging responsibility for parents and professionals. In this our 23rd education issue, parents and professionals discuss this challenge—they share stories of successes, along with ongoing concerns. Many praise inclusive programs; others argue convincingly against inclusion for some children with disabilities. It is clear that experience and research can provide guidelines, but they cannot provide any absolute solutions.

STANLEY D. KLEIN, PH.D.

EXCEPTIONAL PARENT supports inclusion *and* alternatives to inclusion. Most of all, we support the expertise of parents as they endeavor to make wise choices for their children and families.

IDEA: Your support needed

At the national level, we are fortunate that people like Assistant Secretary of Education Judy Heumann continue to advocate for children with disabilities and their families. In this issue, Judy describes current efforts in Congress to reauthorize the Individuals with Disabilities Education Act (IDEA). The IDEA, a law signed just 20 years ago, has revolutionized our country's approach to the education of children with disabilities. We applaud Judy and her colleagues for proposing important "parent-friendly" modifications in the law—more parental participation, mediation of disputes and support for Parent Training and Information Centers. At a time when many political leaders argue for dramatic change, we urge our readers to speak up in support of the IDEA's reauthorization and these proposed modifications.

1995 EXCEPTIONAL PARENT Education Awards

In collaboration with the National Association of State Directors of Special Education (NASDSE), we have recognized programs that illustrate quality education for all children. These programs demonstrate what can happen when dedicated professionals and parents work together to assure that every child is welcome and every child learns. Good education requires far more than philosophies and finances; most of all, it requires caring, thoughtful people who know that delivering quality education is always hard work.

Although most awards go to inclusive settings, we also honor programs that are not as inclusive as some would advocate. We believe that all children—with or without disabilities—deserve an education that respects their individual needs.

Respect for differences

Many recent issues have featured "Readers Talk About," a forum for parents to discuss perspectives on a variety of subjects. Sadly, differing opinions about education are not always respected. Some people believe every child should be educated in the regular classroom and criticize parents who decide their children are best served in other types of programs. Similarly, EXCEPTIONAL PARENT has been criticized for accepting advertisements from and writing about private educational and residential programs. This all-too-common climate of animosity makes this issue's "Readers Talk About" that much more impressive; in story after story, parents with strong individual opinions on educational placement go out of their way to express respect for those who have made different choices. These parents understand the message EXCEPTIONAL PARENT tries to express in every issue—that good choices for children are more important than loyalties to ideologies that too often ignore the fact that parents know their own children best.

To be continued...

Because we have an abundance of important material on education, we will present more articles on this topic in the October issue. We appreciate the assistance we received from NASDSE—an organization that deserves an award of its own—and the efforts of everyone who submitted award nominations.

EXCEPTIONAL PARENT
Parenting Your Child or Young Adult With a Disability
The Magazine for Families and Professionals
Since 1971

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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 82.

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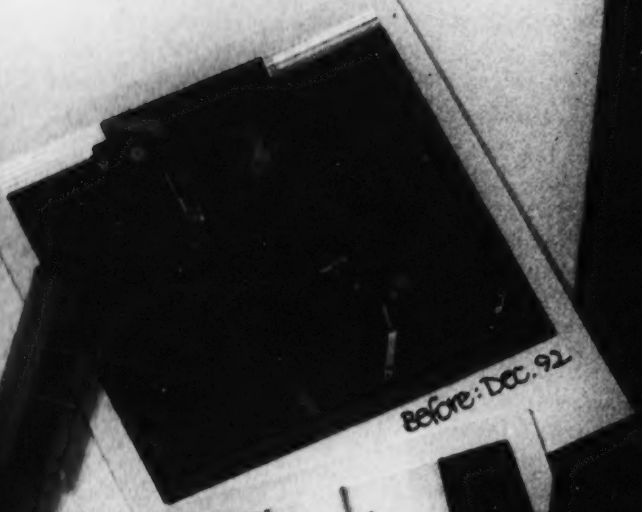
Progress Report



Outcomes: Posture, function, and mobility improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.

LETTERS

Thanks!

I've been reading your magazine for almost five years. I've loved every issue and read each one cover to cover.

Through your magazine I've found a diaper service for my six-year-old daughter and discovered equipment that she could use. But most of all, your magazine has helped me to accept the way our lives have turned out. Your articles always have something to do with what's happening in our lives. Thanks for a wonderful way to keep in touch with others who understand.

Lynn Schiermeyer
Arlington, Texas

■ Seminars, parent group meetings, mail correspondence with others—I've been there, done that, tried it. My true strength has come from everyday life with my son and from EXCEPTIONAL PARENT.

I look forward to each issue with such enthusiasm. Although the stories in the magazine are about children with a wide variety of disabilities, they are all portrayed so honestly. The stories and pictures are from the very best source—parents. And even if some of the stories are sad, they make our family stronger and more appreciative of life with our son, Michael Junior.

Thank you for showing our children in their true light. They are all beautiful, and they all deserve to be seen and heard.

L.Z., New Jersey

Safety First!

I have been very surprised at some of the advertisements for bicycles in EXCEPTIONAL PARENT. Even my two-year-old son could see the problem with these ads. He looked at the pictures and said, "They're not very safe, Mommy." He was right! Both ads pictured children riding bikes *without helmets.*

I am quite sure your magazine does not want to promote the creation of more children with disabilities by encouraging head injuries. EXCEPTIONAL PARENT owes its readers sensitivity to safety issues and responsible advertising for products.

I called the toll-free number for one of these advertisers. When I complained that the children in their ads were not wearing helmets, I was told that was intentional—so the photos would "look good." Has this advertiser thought about how the potentially devastating results of an accident without a helmet would "look?"

Three cheers for parents and caregivers who teach their children that helmets mean safety. When neighbors ask my children why they wear helmets, my kids reply that it's "because Mommy loves me."

I hope EXCEPTIONAL PARENT will ask future advertisers to put safety above "looking good." Please be a responsible magazine.

Marie Baca
Bear, Delaware

EDITOR'S NOTE: We agree. We have asked our advertisers to revise these ads.

These Ads Don't Belong Here!

I subscribed to EXCEPTIONAL PARENT magazine for up-to-date information and support as I raise three children

continued on page 6

EXCEPTIONAL PARENT
The Magazine for Families and Professionals

To reach out to parents of children and young adults with disabilities and special health care needs and to the professionals who serve families

To empower parents and professionals by providing practical information and emotional support.

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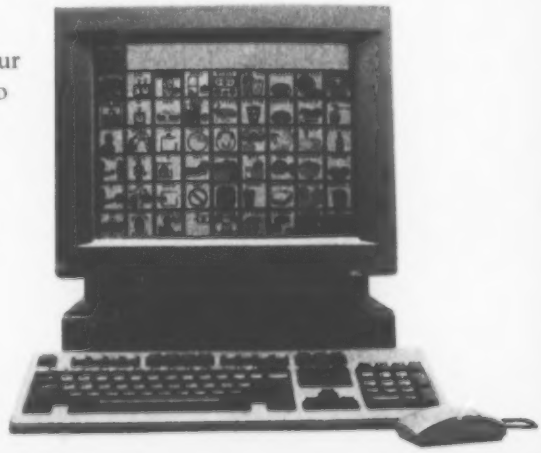

742

Sentient Systems *Technology, Inc.*

Circle #161

For more information on Apple products, contact us at 800-600-7808, 800-755-0601 (TTY), or on the Internet at applewdsg@eworld.com.

Apple

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continued from page 4

with developmental disabilities. You say the purpose of the magazine is "to reach out to parents..., to energize parents... and to empower parents..." Many of your articles accomplish these goals and are uplifting as well. I thoroughly enjoy most of the features and read the magazine cover to cover.

However, I am deeply offended by some of the advertising. EXCEPTIONAL PARENT should not be a forum for those who advocate segregating members of our society at a "residential school in a beautiful country setting"—why don't they just say "institution?" Why should the parents of a beautiful child with Down syndrome be forced to read, month after month, that their child belongs at a school "where persons with Down syndrome find quality life experience?"

All people belong in the community with one another. Everyone's life experience is enhanced when we're together—not segregated. Please take the position that these ads don't belong here.

J.V.S., Colorado

EDITOR'S NOTE: Since the first issue of the magazine in 1971, EXCEPTIONAL PARENT has consistently supported good educational and housing choices for children and adults with disabilities. In that context, we welcome advertising from accredited, private educational and residential programs. Periodically, we receive letters like yours, objecting to this policy. In the 1960s and 1970s, I visited inhumane institutions; now, I visit many of our advertisers' programs. It is unfair to equate these private programs with institutions. I urge you to visit some of these programs and let me know what you think. In this issue, EDITOR'S DESK, RESPOND and READERS TALK ABOUT also discuss the need for parents and children to have choices.

Tell us about...

... your child's and family's experiences with early intervention.

***Write to:** Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

"Bringing up Grandpa"

My husband and I are grandparents raising a six-year-old girl, who has been diagnosed with "features" of autism and cerebral palsy. We are so pleased to have the opportunity to subscribe to your magazine.

She is a bright, beautiful little girl who doesn't look like she has any disabilities. But spend five minutes with her, and you will realize she cannot carry on a "normal" conversation, nor does she walk. We have never seen another child like her. We have seen kids with cerebral palsy and kids with autism, but none like our granddaughter. Even medical professionals don't have any answers.

In the meantime we take her everywhere we possibly can to get answers. People are always telling us, "She is so lucky to have you."

I always reply, "No! We are lucky to have her!"

I will close with one little story about our lives; I guess you could call it "Bringing Up Grandpa." Recently, I pulled a ligament in my knee, and doctors put me on bed rest. That meant Grandpa had to get Kelsi ready for school. The first morning, he brought her into the bedroom to say good-bye to me. He was so proud that he had gotten her ready for school. Her face was still sticky from the pancake syrup she'd had with her breakfast. She was wearing a pink turtleneck and a pair of red and white pajama bottoms! But her hair was combed, and the smiles on their faces were such a delight to see... but, I had to tell him that Kelsi couldn't go to school in her pajamas!

R.T. & S.T., Oregon

743

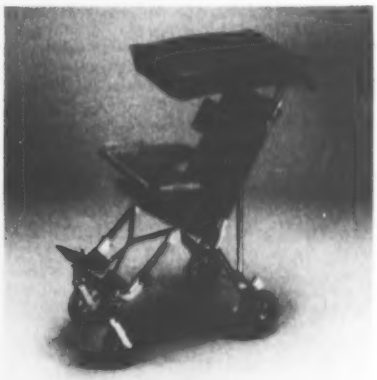
PRODUCT NEWS

Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use. **Circle # 209**

Full Range of Accessories

A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.



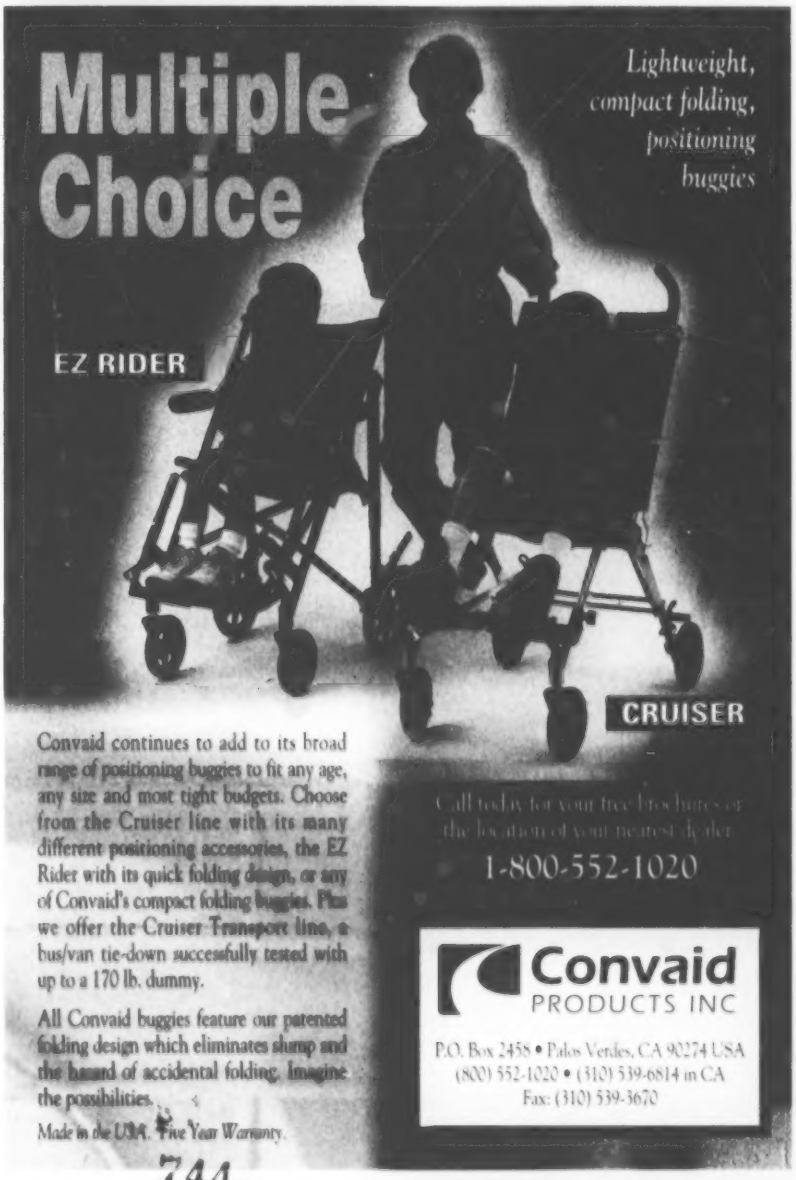
Circle # 208

New Bus/Van Tie-Down Models

Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.

Good Looks, and Custom Comfort Make Kids Smile

Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability. **Circle # 210**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CRUISER
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Circle # 126

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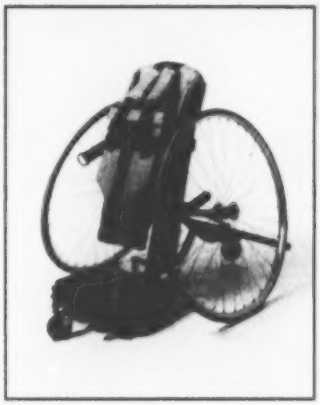

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COVERAGE AVAILABILITY VARIES BY STATE

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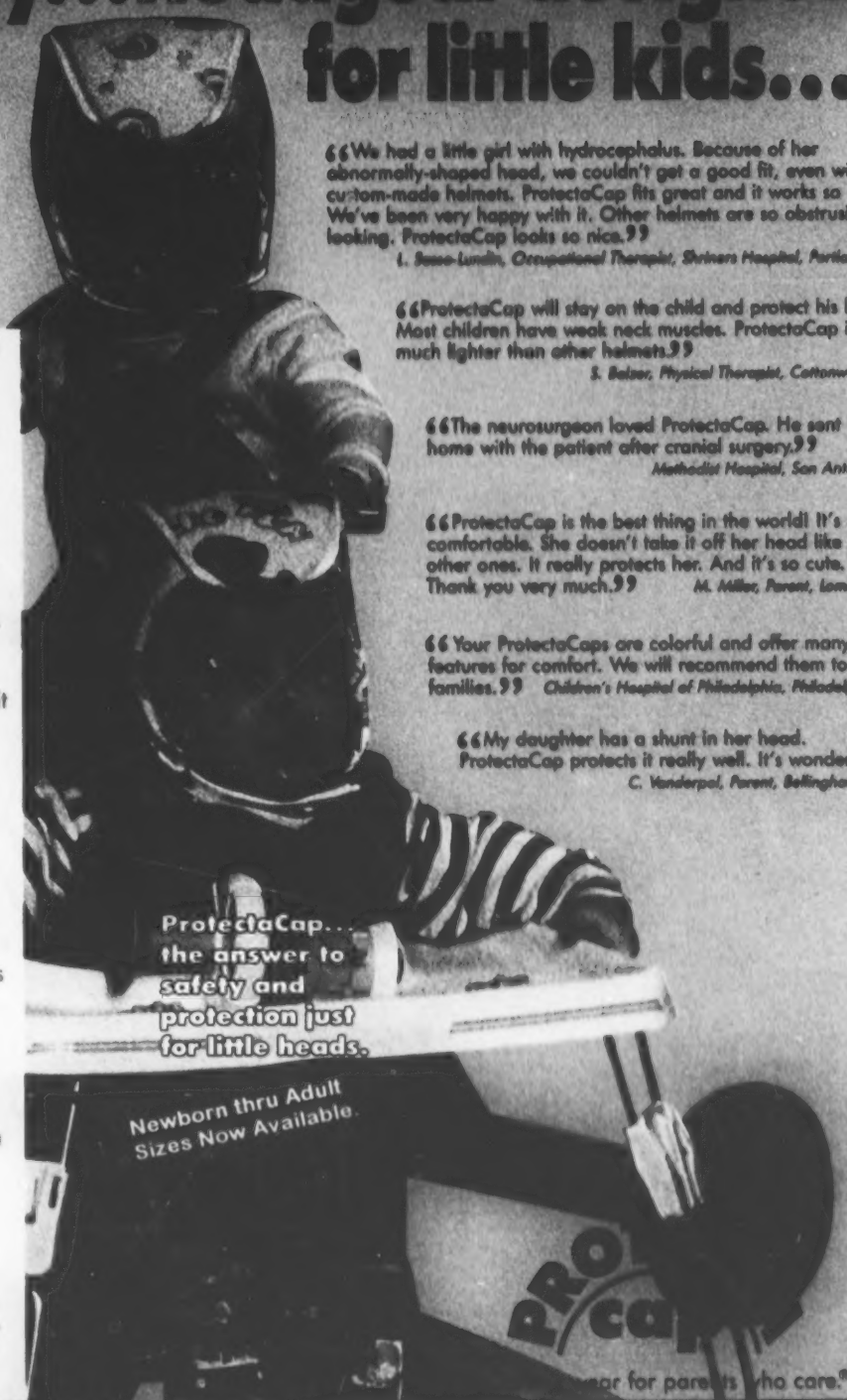
Tested by safety engineers, ProtectaCap rates "excellent" in shock absorption. It replaces hard plastic by eliminating weight, heat, bacteria and discomfort.

Little heads are secured quickly with a convenient Velcro® closure. And ProtectaCap is fully machine-washable.

ProtectaCap is cute, colorful, and adds to the self-esteem of any child requiring headgear.



"We had a little girl with hydrocephalus. Because of her abnormally-shaped head, we couldn't get a good fit, even with custom-made helmets. ProtectaCap fits great and it works so well. We've been very happy with it. Other helmets are so obstrusive-looking. ProtectaCap looks so nice."
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"ProtectaCap will stay on the child and protect his head. Most children have weak neck muscles. ProtectaCap is so much lighter than other helmets."
S. Belzer, Physical Therapist, Cottonwood, AZ

"The neurosurgeon loved ProtectaCap. He sent it home with the patient after cranial surgery."
Methodist Hospital, San Antonio, TX

"ProtectaCap is the best thing in the world! It's so comfortable. She doesn't take it off her head like the other ones. It really protects her. And it's so cute. Thank you very much."
M. Miller, Parent, Lombard, IL

"Your ProtectaCaps are colorful and offer many good features for comfort. We will recommend them to our families."
Children's Hospital of Philadelphia, Philadelphia, PA

"My daughter has a shunt in her head. ProtectaCap protects it really well. It's wonderful."
C. Vanderpol, Parent, Bellingham, WA

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Circle #12

SEARCH

Undiagnosed

My daughter is now two years old. Her initial physical development was precocious. By nine months she was pulling to a stand and "walking" by holding onto furniture. At that point, however, her motor development seemed to stop. She walked unassisted at 21 months, but has poor fine motor control and slightly low muscle tone. She has no speech and few sounds, however, she seems to understand everything we say. She communicates through pointing, some signing and leading me to what she wants. She continues to have poor balance, and "fixes" her body at the joints for stability. She drools continuously and thrusts her tongue when drinking. She resists cuddling—unless she initiates it—and is very defensive about her face and mouth. She has extremely acute hearing, is easily distracted in group settings and is very active.

She has had the following tests: a brain MRI, hip X-ray, blood and urine tests for enzyme deficiencies and long-chain fatty acids, thyroid test, PKU screen, basic chromosomal testing and an audiogram. These tests revealed no abnormalities.

She has slight epicantal folds (vertical skin folds at the inner corner of her eyes); narrowing down the midline of her face, resulting in a high, narrow palate and nostrils; flat fingernails; fetal pads on her fingertips; a wide, flat ribcage and a few other mild physical anomalies. But geneticists cannot link these traits to any syndrome. Doctors have no more suggestions for diagnostic testing. I'd like to hear from anyone who knows of a similar child.

R.H., Connecticut

Infantile Spasms

My 14-month-old daughter is diagnosed with infantile spasms. Her disorder is the result of a stroke at 12 days of age. She has been slow in developing motor skills and has feeding problems.

I would like to talk to other parents of children with a single diagnosis of infantile spasms. I can't find much literature on the subject, so it is difficult to know what the future may hold.

N.M., Illinois

EDITOR'S NOTE: For more information on infantile spasms, see Dr. Hirsch's ASK THE DOCTOR column in the March 1995 issue of EXCEPTIONAL PARENT. You may also wish to contact the Epilepsy Foundation of America (4351 Garden City Dr., Landover, MD 20785-2267; 800/332-1000, voice; 800/332-2070, TTY), the American Epilepsy Society (638 Prospect Ave., Hartford, CT 06105-4298; 203/586-7505) or Epilepsy Canada (1470 Peel St., Ste. 745, Montreal, PQ H3A 1T1, 514/845-7855).

Seizure and Stroke

Our four-year-old daughter, Randee, was born with hydrocephalus and received a shunt at 11 weeks. She had slight developmental delays, but did really well until she was two and a half. At that point, she needed a shunt revision and developed tonic-clonic seizures. During a status seizure, she suffered a stroke. Randee was in a coma for eight days, and in the hospital for 68 days. When released, she was two years, 10 months old, and her developmental level was evaluated at four to six months.

Now, two years later, Randee walks with assistance, climbs on furniture, feeds herself finger foods and understands some things we say to her. One major problem is that she bites everything she gets her hands on—not just mouthing, biting!

I haven't found any other kids who have had a stroke as a result of a status seizure, nor can anyone give me advice about Randee's biting. I would love to hear from parents who have had similar experiences.

R.D., West Virginia

It Isn't Fair!

We are parents of two beautiful boys. Seven-year-old Brett has Down syndrome. His younger brother, Taylor, is two years old and has neuroblastoma (cancer of the neural cells). He has

continued on page 14

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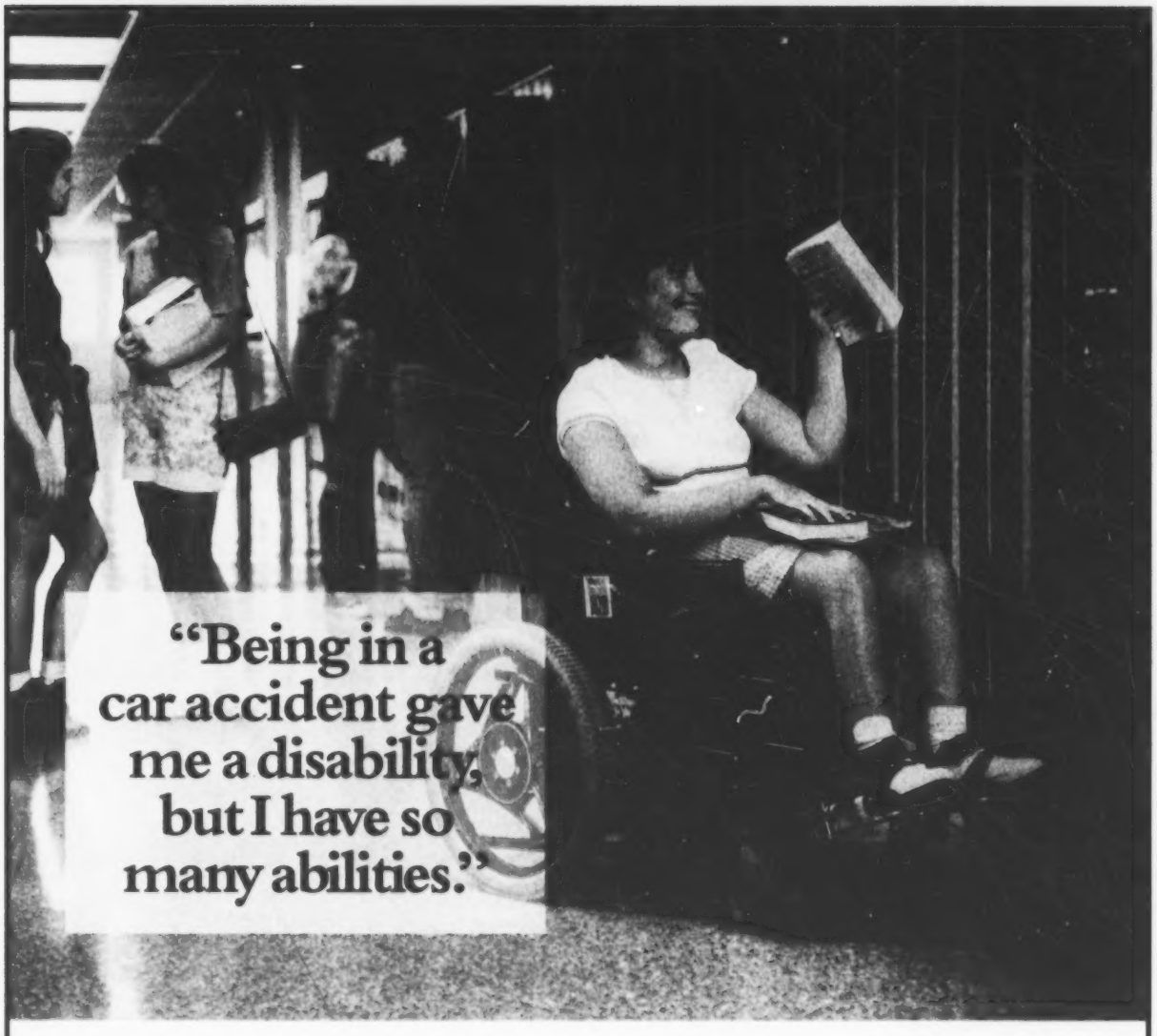

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Circle #37

SEARCH

continued from page 11

been in remission for ten months. Now he is going through more chemotherapy in preparation for a bone marrow transplant.

This just seems so unfair to us. Everyday, we ask how God could do this to us twice. It just seems so overwhelming to deal with two children, who both have problems. We would love to hear from other families who have dealt with similar situations.

K.S. & K.S., New York

Cerebellar Atrophy

Our 28-month-old daughter's recent MRI (magnetic resonance imaging) showed significant cerebellar atrophy since her previous MRI at seven months. The doctors just say, "This is interesting." Our daughter is undiagnosed. She has developmental delays in all areas with low muscle tone and a seizure disorder. We want to talk to families dealing with a similar condition.

L.B. & M.B., Minnesota

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond,
Exceptional Parent
209 Harvard Street, Suite 303, Brookline, MA
02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (V/TTY).

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Circle #14

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Circle #180

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Circle #98

RESPOND

Residential Care

K.S. (July 1995) has a three-year-old son diagnosed with infantile spasms, microcephally, mental retardation and autism—conditions causing severe behavioral problems. Exhausted, and feeling unable to provide the extensive care her son needed, K.S. placed her son in a residential care facility. Heartbroken, she wanted to hear from other parents who have gone through the same experience.

At a time when so many children with severe disabilities are cared for at home, it's hard to find understanding for families where this just isn't possible. Although our situation is different in detail than yours, I thought I would share our experiences.

Our daughter, Emily, has profound mental retardation, cerebral palsy, scoliosis, a seizure disorder and other disabilities. I was constantly tired from all the trips to doctors and therapists—along with six tube-feedings a day—but when Emily was young, I coped. But as she got older and heavier, it became more difficult. Try lifting a six-year-old with the muscle tone of an infant. At best, it was difficult; other times, it was impossible. Sometimes, Emily missed school because I couldn't get her dressed. Other days, she stayed home because the one-hour bus ride was too strenuous for a medically-fragile child. She missed more than a quarter of the last school year she lived at home.

Meanwhile, we'd had two more children. At the time, we thought Emily might eventually learn to sit unsupported and feed herself, and figured we should get the pregnancies over with before she became much heavier. Life wasn't easy for my young sons either; while other kids went to museums and parks, we went to doctors and therapists.

We began the placement process when Emily was six and moved her when she was seven and a half. Our sons were four and two. As a lifelong Episcopalian, I found the church, as well as society, sadly lacking any ritual to help families with this type of transition. One Sunday, we requested prayers "for Emily, who is entering a new school." Our church prays for people who are getting married, joining the Army or going through other life changes, but our prayer request was a new one. As it turns out, now that I'm no longer perpetually exhausted, I can bring Emily to church almost every time she comes home—every other weekend—which is more than I did when she lived at home.

To help our sons, we made sure they got a good look at Emily's school. The first evening after her move, our two-year-old son worried his sister wouldn't get any dinner because he didn't think the school had a kitchen; we made sure he saw the kitchen on his next visit! Our older son wanted to write a letter to the school staff, so we helped him with that. We also used little "tricks" to help the boys look forward to her visits—such as saving special toys for her weekends home.

Relationships with school staff are important. When Emily had surgery after about eight months at this school, staff members visited regularly. I watched Emily's face light up when they came into the room. It's important to realize that staff members have bonded with Emily and consider her to be "theirs" in some ways. For example, with our consent, they let

continued on page 20

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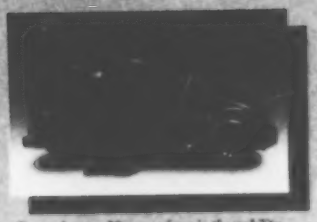

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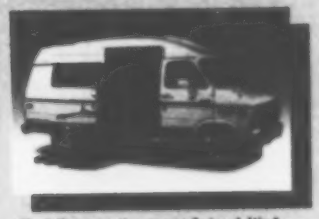

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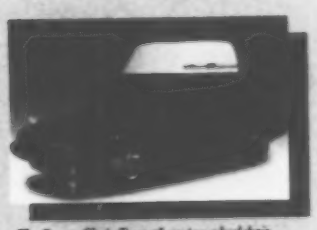

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Circle #112

continued from page 16

her hair grow long and "do it up" in fancier braids than I would ever try. They also choose some of her clothes. This does not mean we give up control on important issues, but we know we need to allow the staff to enjoy Emily.

Obviously, no school is perfect. But Emily's life at home was also far from perfect. Neither do Emily's brothers enjoy the luxury of perfection—at home or at school. Life isn't perfect anywhere; we just do the best we can.

Our close friends—the ones who watched me struggle to care for Emily—understand why we made this decision. Other, well-meaning friends hint that Emily would be better off at home, or that we just didn't try hard enough. I've memorized a few pat answers: "Emily is so lucky that special education is year-round at her school" or "She's so much better rested now that she's not riding a school bus two hours a day." Then I just change the subject. Any concerns you feel about your son's residence—and there always will be some—are best shared with just a few very close relatives or friends.

M.D., Maryland

■ I know how you're feeling. My daughter, Becky, now 15, was born with an occipital encephalocele (an opening in the base of the skull through which the brain protruded). This resulted in blindness, cerebral palsy and severe mental retardation. Becky requires total care.

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On the other hand, Becky has grown so much in the past year. We visited her last week and were so pleased to watch her bring a spoon to her mouth to feed herself—a new skill! It helps to see Becky learning new things and growing in ways she could not have done at home. Best of all, Becky now has a friend! Like Becky, Jenny has severe mental retardation, but I feel so good to see the two of them relating to each other as any two buddies.

The hardest part was giving Becky's care over to other people. I'd done everything for her, for more than 13 years—feeding, changing, bathing and dressing. These rituals were a big part of our relationship. As my two other children grew up, I watched them gradually do more and more things on their own. But with Becky, one day, I was caring for her totally; the next day, I was doing nothing for her. What a shock!

The people at Becky's school have been wonderful, and have helped me understand that an adjustment like this takes time, and that all my feelings are normal. I hope my story helps you, and I hope you hear from other parents, too. I'm still adjusting myself; after one year, the pain is still there, but it has lessened.

D.E., Ohio

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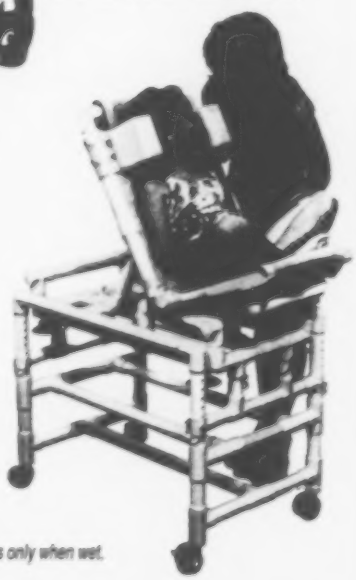

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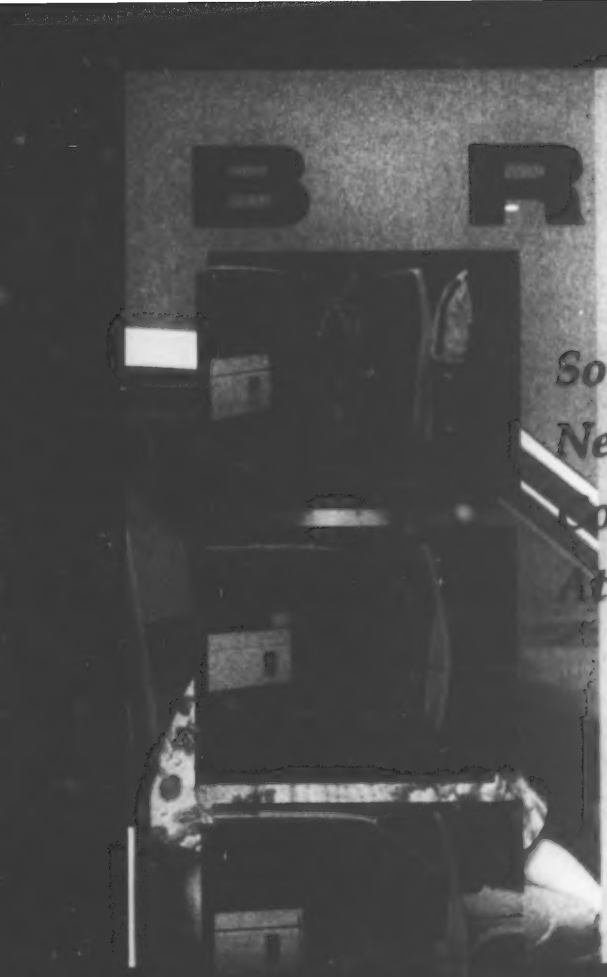

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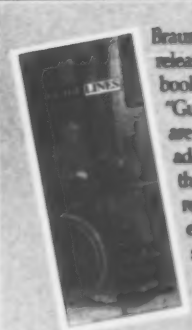

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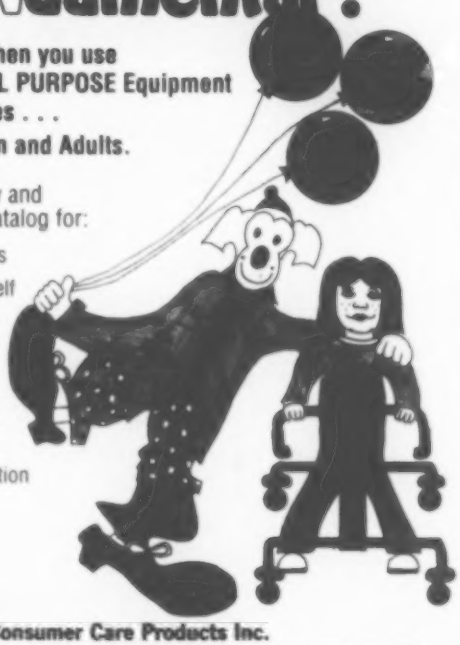

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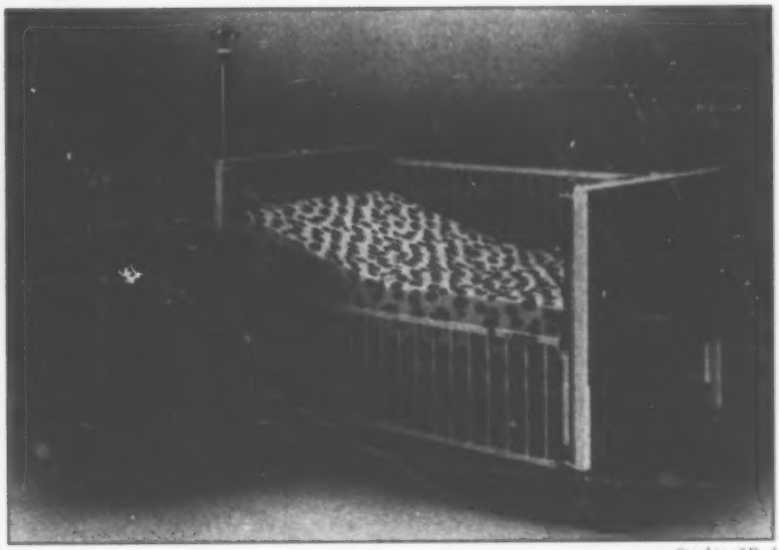

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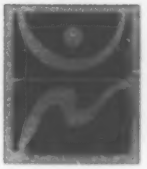

Faces of the Special Olympics World Summer Games

Although the competitors at this year's Special Olympic World Games in New Haven, Connecticut represented over 140 countries, they were united by their commitment to athletic excellence, sportsmanship and, of course, fun!

EXCEPTIONAL PARENT is honored to recognize the outstanding efforts of the participants and their supporters. Here are some of the faces of the 1995 Special Olympics World Summer Games:

Daxton Miller, 16, of Wichita, Kansas (left) and doubles partner Darren Hodgson (right) get a pat on the back from tennis star Pam Shriver (center) at a ceremony honoring their achievements. Daxton, who has mild mental retardation and was competing for the first time in the World Games, won a gold medal in the singles competition and a bronze in the doubles competition. "He felt really good about being involved," says Daxton's father, Harold. "He thought it was nice to meet people from different countries. He enjoyed the competitive nature of the games." Recognizing Daxton's achievements, Wichita mayor Bob Knight proclaimed July 18, 1995 "Daxton Miller Day."

Twelve-year-old **Nicole Lowrie** of Largo, Florida warms up for her balance beam routine. Nicole has an atrial septal defect—a hole in her heart, attention deficit disorder, a cleft palate and mild mental retardation. She received three medals in the gymnastics competition including a gold in floor exercise, a silver in vaulting and a gold for her overall score. Nicole's developmental psychologist originally suggested gymnastics as a sport that could boost Nicole's self-esteem—advice that appears to have been accurate! "I had lots of fun, made new friends, and all the hard work was worth it," says Nicole.

Swimmer **Rusty Corley**, 17, of Jamestown, North Carolina (seated) steps onto land for a moment to smile for the camera with his twin brother, Robbie (standing). Rusty, who has cerebral palsy and hydrocephalus, won a gold medal in the 25-meter freestyle and a bronze in both the 50-meter freestyle and the 25-meter relay. "He went to win, but he also went to have fun. He did both," said his mother, Bea. Though this was Rusty's first time competing in the World Games, he has competed in the North Carolina State Special Olympics for the past five years. Rusty wasn't sure at first that he'd like competing again but decided that winning "felt pretty good."

Jon Derr, 16, of Swampscott, Massachusetts, gives us another reason to salute—his bronze medal in the golf competition. Jon, who has Down syndrome, had the support of more than 200 counselors and fellow campers from Camp Ramah of New England in Palmer, Massachusetts, who came in three school buses and two vans to watch their friend take the green. Although he didn't win the gold, Jon realizes it's his commitment that matters. "I did my best," he says. "That's what counts."

Written and compiled by Jason Roeder, editorial intern.

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Familiar Faces

Blake Austin, 11, (second from left) of Littleton, Colorado, is a very enthusiastic percussionist in his school's sixth-grade band. Blake, who has multiple disabilities including cerebral palsy, mental retardation, visual impairment and a seizure disorder, seems to have a knack for beating obstacles as well as the drums. "Blake is the first student with severe disabilities to be in band at his school," writes mom Stephany. "It's his favorite class."

Brock Davis, 6, (left) and best buddy Keegan Witherow put on a puppet show for other members of their kindergarten class in Muscatine, Iowa. Brock, who has cerebral palsy, is a "pretty popular guy" with his classmates says mom Barbara. She adds, "We firmly believe that Brock's inclusion has enhanced his motivation to learn and be independent—just like all his friends."

Lean on me! **Emily Jean Mailman, 4,** (right) of Windsor Locks, Connecticut, gladly shares a shoulder with her best friend **Allison Pepin, 2.** Emily has Down syndrome "but in our neighborhood," write parents Linda and Matt, **"she is just one of the gang and participates in all outdoor activities with her buddies."**

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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The MED New Equipment Warranty Service (NEWS), which can be purchased from any MED-certified repair center, helps consumers and parents avoid the high cost of equipment repairs and keeps children and adults with disabilities on the move! NEWS provides warranty coverage equivalent to the original manufacturer's warranty, including coverage for up to three years from the date of purchase. No out-of-pocket expenses on covered repairs means extra peace of mind!

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NEWS covers repair costs, including parts and labor. In fact, while the equipment is covered by the original manufacturer's warranty, NEWS covers labor costs, which may not be covered by the original warranty. After the manufacturer's warranty period has elapsed, NEWS continues to cover the same repairs covered by the original manufacturer's warranty. There are no deductibles or co-payments for covered repairs.

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Training consists of three levels. At the first level—*Bronze*—technicians are certified to perform manual wheelchair repairs within a set period of time. They learn to work efficiently and provide accurate estimates on repair costs. At the next level—*Silver*—technicians are certified to perform power wheelchair repairs within a set period of time. They know electronic fundamentals and can locate and eliminate sources of trouble in major manufacturers' products. At the highest level—*Gold*—technicians learn advanced electronic theories and can supervise other technicians.

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The MED National Repair Center provides comprehensive technical support to the national network of MED-certified repair centers. The MED National Repair Center experts provide assistance by telephone when

a technician is trouble-shooting a difficult problem; they walk the technician step-by-step through repair procedures. This service saves both time and money.

The MED National Repair Center stocks an extensive inventory of electronic components that meet or exceed manufacturers' specifications for quality so customers don't have to wait while parts are on order.

Every employee of a MED-certified repair center is committed to upholding the high standards of quality, service and ethics that are the foundation of the MED group. This means taking our slogan to heart—*"dedicated to improving the quality of your life."*

Any MED-certified repair center can provide the necessary information to purchase a New Equipment Warranty Service plan.

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On a family vacation, Nicholas and Dad get ready to take the boat out for a spin on Pelican Lake.

Building our Future

by Mark Brown

Remember when you were young and built a snowman or a sand castle? You were so proud. Then, the next day, you went out to the back yard or down to the beach and found total devastation.

That's how I felt the day my son was born. When the day started, I was filled with excitement and anticipation; just hours later, I was running down the hospital hallway beside my sister-in-law and a nurse, who was pushing my wife's stretcher into the emergency room. Days seemed to pass before the doctor came out and said my wife was fine, but the baby might not make it.

My new son, Nicholas, was going to be sent to Children's Hospital, and I went along. The ambulance ride seemed to last forever! I kept wondering if my son would live and how my wife must be feeling, all alone at the other hospital. What a mess! How could something so beautiful turn so ugly?

The doctor at Children's Hospital said that Nicholas had suffered oxygen deprivation and was having seizures. Nicholas was on a lot of medication and the doctor told me, "The prognosis isn't good, but time will tell. Kids are tough."

I didn't want to leave for fear Nicholas would die without family by his side. So I waited. And every day, as I waited, the medications started to wear off. Finally, Nick started to wiggle.

During those long days by his bedside, my son became a passion. "Think positive!" I kept telling myself. I sang to Nick, read to him, talked to him; I still don't know if I did all those things because I was tired or because I was going crazy. Then one day, exhausted, I fell asleep next to Nick's bed. When I woke up and looked at him, he was looking back at me! At that moment, I knew he was going to live. I was so happy. I felt a burning deep inside my heart.

On his second birthday, Nick found a way to have his cake and eat it too.

Finally, Nick's mom got to visit for the first time. That visit made me realize why God made moms and the important role they play in a child's life. Nick started eating a little. After nine days in the hospital, Nick was ready to come home.

For our family, everything changed the day Nick was born. Nick ended up with a diagnosis of cerebral palsy. Our life consists of braces, doctors, testing, neurologists, eye patches, physical therapists, occupational therapists, adaptive equipment, tight schedules and a whole lot more. But our family and friends have come together to give us love and support.

Though Nick is only two years old, he has accomplished so much. Yes, Nick has disabilities—he can't walk, talk or sit very well. But he can smile, laugh and cuddle. He can nod "yes," shake his head "no" and make the sign for "music." He hugs and gives kisses. Nick is beautiful, he's ours and he's here!

Our whole family keeps building those snowmen and sand castles—no matter what the next day brings. Every day, we hope to build one better and stronger than the one we built the day before. **EP**

Mark Brown lives in Shakopee, Minnesota with his wife, Audrey, and their children, Ryan, 9, Kelly, 6, and Nicholas, 2. Mark is a manager at Anchor Glass Container Corporation. In his spare time, he enjoys hunting and fishing.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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Suzanne Miller

"You can do everything with one hand"

Suzanne Miller, 54, has taught elementary school for 28 years—the last 25 as a special education reading teacher in the Waukegan, Illinois public schools. She works primarily with students who have learning disabilities. Miller suffered a stroke at 14 months, which weakened her vision and the left side of her body. The following was adapted from an interview between Miller and EXCEPTIONAL PARENT *intern Michele San Filippo.*

The Miller family (from left)—Jane, Margaret, Suzanne and Frank—celebrated Suzanne's 1960 graduation from Framingham High School in Framingham, Massachusetts.

I was perfectly healthy when I was born. Then one night, when I was 14 months old, I got very sick. My parents put me to bed, but I didn't wake up the next morning. They rushed me to the hospital, where doctors said I had polio. Four years later, however, a doctor from Temple University looked at me and said, "This young lady never had polio—she had a stroke or a cerebral hemorrhage."

As a young child, I attended a "regular" nursery school, then went to parochial school. I had a difficult time adjusting to wearing my leg brace. The other children used to make fun of me. In the fifth grade I also got glasses; not only did I limp, now, I was a "four-eyes," too.

My father worked as a sales manager for Oscar Meyer and Hi-Grade Food Corporation, so we moved around a lot. My sister, Jane, hated moving and used to get mad because I would be so excited to hear about our next move. I would clap my hands and say, "Yippee!" I must have thought that by moving to a different state, I could forget my bad experiences in school and start over.

Tough love

It didn't matter what happened at school—at home, my parents emphasized that I was no different from anybody else. I remember one day I dropped a piece of paper on the floor. I expected my parents to pick it up. They refused. I said to my father, "Well, if you're gonna do this to me, then I'll just run away."

He opened the door and said, "Good. Leave."

And there I was—out on the porch. It was wintertime. It was snowing, and my father wouldn't give me a coat! I kept banging on the door.

"Are you coming in?" he asked.

"Yes."

"Fine," he told me. "Now go pick up that piece of paper."

"No!"

We went through this routine four times. I was getting colder and colder. Finally, I came in and picked up the paper. What can I say? I'm stubborn!

My parents stressed independence for my sister, too. They wanted her to have her own life. When I would drop things, Jane would run to pick them up, but my parents would tell her, "No. Don't do that. You have to let Sue take care of herself."

Suzanne, 6, enjoyed riding her tricycle around the neighborhood.

High school

My high school years were difficult. During my freshman year at Springfield High School in Springfield, Pennsylvania, I had to have a lot of orthopedic surgery. And by my junior year, my family had moved again—this time to Framingham, Massachusetts. In many ways, I was a typical teenager; I wanted to be included in all the activities, but wasn't always accepted.

Even in high school, I knew I wanted to be a teacher. But because of my hang-up about my disability, I came up with the idea that I would become a teacher for children who were blind—because they wouldn't be able to see my disability.

"I referred myself!"

After graduating from Butler University with a degree in elementary education, I started applying for teaching positions in public schools. I'd make it through the screening process and get an interview. But "mysteriously," I was never offered a job. I finally found a two-year position teaching fourth grade at a parochial school. But when they didn't ask me to continue, I was back where I started.

At this point, I remembered what one high school counselor had told me—"If you ever run into any problems with

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employment, remember the federal government has an obligation to see that you are employed." So I looked up the state vocational rehabilitation commission and made an appointment.

As soon as I walked into the office, they asked, "Who referred you to us?"

I said, "I did."

Then they asked again, "No. Who sent *you* to *us*?"

I said, "You don't understand. *I* did... I feel I am being discriminated against, so here I am."

Vocational rehabilitation enabled me to go to Northern Illinois University and get my master's degree in reading. They told me to pay for the first semester, and if I got through it with good grades, they would pick up the tab for the rest.

Getting into special education

I never intended to go into special education; I just knew I wanted to help kids learn to read. I enrolled in an introductory special education course only because at that time, you needed at least one special education course to get teaching certification in Illinois.

When I was close to graduating, I went for an interview with the Waukegan public schools. And the interview turned out to be with the director of special education. The position would involve teaching reading to children who were in special education. I got the job, and I've been teaching in the Waukegan public schools ever since.

During the last 25 years, I've seen special education come a long way. The children are a constant challenge for me. You can't baby these children; you have to respect them. You have to set limits and provide structure. As educators, we have to get our students ready for the working world, and enable them to help themselves.

Sometimes, I feel my disability gives me an advantage over other teachers. I can ask a child, "Would you like to help me do this? You know I really can't do it very well." By letting them see my strengths and weaknesses, they learn to see their own. They always say things like, "Well, I *can't* read" or "This is hard for me." And I say, "Well, I can't run and jump."

Sooner or later, the kids always want to know what's wrong with me. When they ask,

Suzanne and younger sister, Jane, helped their father celebrate his 80th birthday at his home in Florida.

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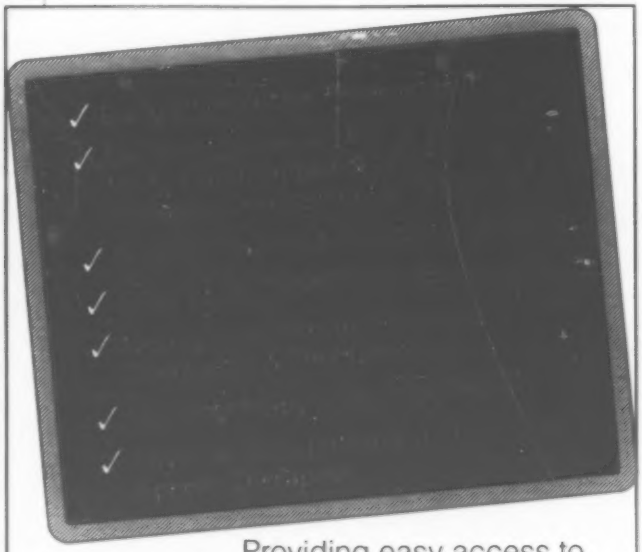

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Circle #77

Role Models

continued from page 31

I just tell them, "I was sick as a baby," and let the subject drop. Then I wait. About three or four weeks later, they start raising their hands and asking questions: "How do you wash your hair?" "How do you take a bath?" "Does somebody live with you to take care of you?"

One day, one little boy got tired of all the questions and said, "Look, just leave Miss Miller alone. She told you she was sick when she was a baby. And besides, you can do everything with one hand. The second hand just helps the first hand do things faster."

"Miss Miller," as she is known to her students, always encourages her classes to use their imaginations—especially on Halloween! Serving as an example of creativity, she dressed as a scary skeleton (far right) for this class picture.

My most rewarding moments as a teacher are when children I had in the past come back to me and say, "Hey, Miss Miller, remember me? I'm in college now! I have a job and this is what I'm doing..." It's very rewarding to see their accomplishments and to know that I have made a difference in their lives. **EP**

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Circle # 74

Quality: It's Everywhere!

by Gail Lieberman

When I read magazine articles listing good restaurants or recreational areas, I often wonder, "Why isn't there an example from my community? Don't we have one, or is it that people don't know about what we have to offer?" It's the same way when it comes to schools. One school may become a "lighthouse" and attract people from many miles around. Another equally-good educational program may remain the best-kept secret in the state!

For this article, my colleagues on the board of the National Association of State Directors of Special Education helped me identify some hallmarks of quality educational programs. As one board member, John Corpolongo of Oklahoma, told me, "Quality in special education is like quality in any other endeavor. It starts with the assumption that what is being delivered can, and must, be improved upon. With this assumption, special education continually evolves in a dynamic process as families and professionals gain new knowledge and insights."

Interspersed throughout the following 14 pages are profiles of the schools and programs that are recipients of the 1995 EXCEPTIONAL PARENT Education Awards. Even if one of these programs is not in your community, please consider some of the criteria by which program quality can be judged. You may find these signs of quality in your local educational programs:

- A *unified educational program* in which administrators, teachers and parents support the education of all children in a system that values unity rather than segregation.
- *Collaboration* among all staff members.
- Ongoing *professional development* that includes and focuses on families.
- A focus on *problem prevention.*
- Extensive use of *assistive technology.*
- Major *curriculum adaptations* to accommodate student needs.
- *Student involvement in local and state assessments.*
- *Active inclusion* involving interaction with other students rather than passivity and isolation with aides or other adults.
- *Transition support* for the family and student as he or she moves from secondary to post-secondary services.
- *Partnership and commitment* in all activities related to students with disabilities.

Getting what we expect

What do you need to ask of schools and school systems in terms of quality? Consider yourself a shopper seeking to fill an identified need—your family is the "buyer;" the school system is the "seller." In the *California School Board Journal*, Judy Smith-Davis wrote about assessing promising practices in an article entitled "We Will Get What we Expect." Her questions can help you find quality in your community:

- *Claims:* Ask yourself, "What goals and objectives am I looking to fulfill?" Ask the school, "What goals and objectives are your practices designed to achieve?"
- *Effectiveness:* Ask yourself, "How stringently should effectiveness be demonstrated?" Ask the school, "What evidence proves this practice is successful in achieving what it claims?"
- *History:* Ask yourself, "What are the qualities that define my local setting?" Ask the school, "In what administrative, geographical and educational settings has the practice been used?"

Marseilles Elementary School, Marseilles, Illinois

1995 EDUCATION AWARD

Over the past few years, Marseilles Elementary School District #150 (MES) has worked hard to develop the best possible education program for all children—both "regular" and "special needs" students. Because my eight-year old daughter, Mary, who has cerebral palsy, stays in her own town to go to school, she has made many friends she might not have made otherwise. As a result, she is involved in many community activities including church and library activities, horseback riding and swimming lessons.

Mary Hettel, a student at Marseilles Elementary School, gets a hand (or two) from Mrs. Saunders, her personal assistant.

In the past few years, MES has:

- Brought special needs students back to their home school.
- Created a full-inclusion program using all adaptations necessary to meet students' needs.
- Remodeled the school building in compliance with federal and state ADA and IDEA regulations, and even gone beyond requirements by building a three-story elevator.
- Organized an inclusion committee involving teachers, administrators, parents, school board members and community members.
- Provided training for teachers.

MES does its best to help each student meet his or her highest potential. Mary absolutely loves school and for that we are very thankful.

Nominated by Julie Hettel, parent

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• *Implementation:* Ask yourself, "What kinds of training or assistance are needed to implement a new practice?" Ask the school, "How is this practice taught to families of new students or new faculty members? What follow-up and problem-solving assistance is given?"
• *Change:* Ask yourself, "What is my timeline for producing change? What is my criteria for judging success?" Ask the school, "How rapidly does this practice achieve its goals? Do you have evaluation procedures for measuring success?"

CONSIDER YOURSELF A SHOPPER SEEKING TO FILL AN IDENTIFIED NEED—YOUR FAMILY IS THE "BUYER;" THE SCHOOL SYSTEM IS THE "SELLER."

Finding quality in your community

Some signs of quality in your community may be obvious. You may need to discover others, so they do not remain a secret. Still others you may need to create—in partnership with other local families and professionals—for your child and for future schoolchildren.

As my colleague Bill East from Alabama says, "Quality special education is realized when all Alabamians live, learn, work and play in communities where the worth of every person is valued, where individual needs are supported and where opportunities are barrier-free." This statement defines quality education for every community. **EP**

Gail Lieberman is the president of the National Association of State Directors of Special Education (NASDSE). She has been a special educator and has worked for the state of Illinois, in various capacities, for 24 years. Gail is married, and has a nine-year-old daughter. For more information about NASDSE, contact Dr. Martha Fields, Executive Director, NASDSE, 1800 Diagonal Rd., Ste. 320, Alexandria, VA 22314, (703) 519-3800, voice; (703) 519-7008, TTY.

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Common Questions About Inclusion

What does the research say?

by Dorothy Kerzner Lipsky and Alan Gartner

1 What is the definition of inclusion?

There is no official definition of "inclusion." However, based upon extensive study of inclusive programs and consultation with educational leaders, the National Center on Educational Restructuring and Inclusion (NCERI) has developed the following working definition: "Providing to all students, including those with significant disabilities, equitable opportunities to receive effective educational services, with needed supplementary aids and support services, in age-appropriate classes in their neighborhood schools, in order to prepare students for productive lives as full members of society."

2 Are there any full-scale research studies of inclusion?

Inclusive education programs are a relatively new phenomenon. As a result, there have been few full-scale evaluations of outcomes. Researchers have studied individual programs, and several statewide and local evaluations are currently underway.

A statistical technique, known as meta-analysis, allowed researchers Baker, Wang and Walberg to combine results from many studies and compare the effects of inclusive versus noninclusive settings. Their study found "a small-to-moderate beneficial effect" of inclusion on academic and social outcomes, meaning that "special-needs students educated in regular classes do better academically and socially than comparable students in noninclusive settings."

Summarizing several studies in a report to the President's Committee on Mental Retardation, Nisbet concluded that inclusion resulted in positive experiences and improved attitudes for children with and without disabilities, and also for their teachers. She added, "There is also some convincing evidence that integration or part-time mainstreaming does not accomplish the social benefits of inclusion."

In its summary of 10 regional hearings, the National Council on Disability reported that a majority of witnesses testifying on the subject of "least restrictive environment" indicated strong support for inclusive placements. Many parents stated that their children with disabilities made greater academic and social gains in integrated settings. Parents reported that their children were happier in inclusive classrooms and were eager to be doing the same activities as their peers. This testimony reinforces the results of several other research studies and parental reports included in the national studies of inclusive education conducted by NCERI.

3 Are students with mild and moderate disabilities successful in inclusion programs?

Overall, studies comparing differences between inclusive and segregat-

Tobey Elementary School, Vicksburg, Michigan

1995 EDUCATION AWARD

Tobey Elementary School provides a comprehensive program for students with developmental disabilities. Through careful planning involving parents, the staff works to meet the academic, social and recreational needs of these students.

For example, Joseph Manslei, an 11-year-old with cerebral palsy, has attended Tobey, his home school, for the last two years. Joseph requires assistance for feeding, toileting, wheelchair mobility and classroom computer work. The staff has been creative in finding solutions to meet these needs. His classroom has been adapted so he can be either in his wheelchair or a prone stander. He has a full-time health care aide, as well as physical, occupational and speech therapists. He now has a five-minute bus ride to school; he used to have to ride for an hour each way.

Tobey Elementary School student Joseph Manslei (center) joins a teacher and a classmate to explore the world of science.

Joseph has participated in the music program, the science fair and fund-raisers. He joined his classmates when they read stories to kindergartners. He is a member of the student council. Recently, he participated in the McDonald's speech contest using a voice synthesizer.

At his last annual review, Joseph's classroom teacher stated that the past year was rewarding for both Joseph and his classmates. Though originally reluctant to have Joseph leave the center-based program, his mother now feels the transfer to his home school was for the best.

Nominated by Helen Magas, physical therapist; Susan Wolthuis, occupational therapist; and Susan Maston, teacher-consultant

ed settings for students with mild and moderate disabilities have found more behavioral progress and increased social competence in inclusive settings, but limited differences in academic performance.

A study by Jenkins and colleagues, done in 1992, was one of those summarized in Nisbet's report to the President's Committee on Mental Retardation. Jenkins used a standardized test to compare students with learning disabilities in two similar schools. One school served students in the regular classroom; the other used a resource room "pullout" model. Results showed that students receiving all services in the regular classrooms made significantly higher overall gains.

Affleck and colleagues also compared student achievement in integrated versus resource programs. They found only slight measurable differences, however, those differences favored the integrated settings. Deno and colleagues report similar results in a 1990 study. They found that while students with mild disabilities served full-time in a regular class progressed more slowly than their peers without disabilities, they still progressed more rapidly than similar students served in pullout programs.

4 Are students with significant disabilities successful in inclusive classrooms?

Again, studies generally report more favorable social and behavioral outcomes for students with significant disabilities served in inclusive settings. Because most of these students are not included in standardized testing, academic performance is harder to compare, however, several studies report greater achievement of IEP objectives in inclusive settings.

There are several important studies comparing outcomes for students with significant disabilities served in inclusive placements compared with segregated settings. For example, Ferguson found that students served in an inclusive placement had greater success in achieving IEP goals than did similar students in traditional programs; Burello and Wright reported gains in student self-esteem; and Marwell reported greater acceptance by peers without disabilities. Other researchers report greater behavioral progress, greater social competence and at least equivalent academic success in inclusive versus segregated settings.

In two studies, Hunt and colleagues found that students in inclusive classes had IEPs containing more references to effective instructional methods than did students in segregated classes. The researchers also found that students in inclusive settings were more likely to interact with other people in the classroom.

5 Are inclusive preschool programs successful for students with disabilities?

Nisbet's summary of the research concludes that integration has positive effects on the social competence of preschoolers with disabilities. They spend more time playing and verbalizing in positive interactions with peers. Integration opportunities also appear to have positive effects on other behaviors, for example, increased sophistication of play.

Nisbet adds that integrated and segregated settings seem to be equal in terms of measured developmental progress on standardized tests, negating any argument that segregated settings can provide more specialized and effective interventions. Finally, studies report no negative outcomes for "typical" preschoolers attending programs that include students with disabilities.

6 Are inclusive education programs successful for students without disabilities?

A recent research review by Staub and Peck addresses three common concerns related to students without disabilities.

• *Slower academic progress?* Studies consistently find no slowing of academic progress for students without disabilities in inclusive classrooms.

• *Less attention from teachers?* Studies showed that the presence of students with severe disabilities had no effect on

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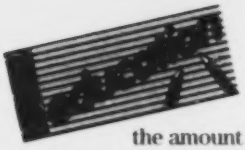

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the amount of teacher attention received by students without disabilities. Furthermore, there was no difference between inclusive and non-inclusive classrooms in terms of instructional time lost to interruptions.

• *Learning of undesirable behaviors?* Evidence indicates that students without disabilities do not acquire undesirable behaviors from peers with disabilities. On the contrary, Staub and Peck identified several positive benefits for these students, including increased comfort with and awareness of human differences, improvements in self-concept and the development of warm and caring friendships.

Helmstetter, Peck and Giangreco reported on a statewide (Washington) study of high school students without disabilities showing more positive outcomes associated with increased contact and interactions with students with disabilities. These outcomes included increased responsiveness to the needs of others, valuing relationships with people with disabilities, increased tolerance of other people, development of personal values and increased appreciation of human diversity. Several other studies confirm these positive benefits.

7 What is necessary for inclusive education programs to be successful?

NCERI's 1994 national study of inclusion programs found the following keys to success: visionary leadership, collaboration between general and special education, refocussed use of assessment, supports for staff and students, funding that followed the child and effective parental involvement.

For school personnel, systematic staff development and flexible planning time for special- and general-education teachers to work together are essential. For students, supports for inclusive education may include cooperative learning (students at different ability levels work together on a common learning task), curriculum adaptations, "hands-on" learning, multi-level instruction (the teacher provides instruction on the same subject, but at different levels, to students of differing abilities), provision of needed therapy services in the regular classroom, peer tutoring and support, buddy systems, effective use of assistive technology and the availability of classroom aides.

Inclusive education does not mean that all services are always provided in the regular classroom; for example, training in Braille and mobility techniques for a student with a visual impairment may require time in a special setting. But inclusion means that the student's basic placement is in the regular classroom and that the class-

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room teacher is trained to support the student's special training in Braille and mobility.

8 Does inclusion place too great a burden on general education teachers?

When teachers are provided with appropriate supports, their experiences are positive. This is confirmed by the studies done by Burello & Wright, the Michigan Department of Education, Giangreco and colleagues, Rainforth, and York and colleagues. Other studies (Chase & Pope, Christmas, McDonnell & colleagues) show that when needed supports are not provided—not surprisingly—teacher attitudes are less positive.

9 What about costs?

The data on special education funding are complicated and the answers not yet clear. The best data come from the federally-funded Center for Special Education Finance, which reports that current funding patterns create incentives for segregated education and disincentives for integrated education.

Districts that have fully-implemented inclusive programs report that, on average, these programs are no more expensive than segregated programs, and perhaps, are less expensive. As researchers McLaughlin and Warren point out, when the costs of providing services in local schools are compared with the costs of transportation and educational services in other settings, inclusion appears to be less expensive. However, for districts to experience actual savings, dollars spent on segregated education would have to be transferred to the home schools of newly-included students with disabilities.

10 Is inclusion appropriate for all students?

The law recognizes and common sense tells us that each child is unique. Educational research cannot identify what will be best for the individual child. The decision about inclusion, or any other educational option, must be made individually—in light of the law, an understanding of relevant research and the family's values.

The law shows a clear preference for inclusion. (See "The Law and Inclusion," page 40.) As the court stated in *Oberti*, "Inclusion is a right, not a privilege of a select few." The decision went on to state that a school district may not place a child with disabilities outside of a regular classroom "if educating the child in the regular classroom, with supplementary aids and support services, can be achieved satisfactorily."

NCERI's 1995 study of inclusive education programs reports on nearly 900 school districts across the country that are successfully educating students with all types of disabilities—at all levels of severity—in inclusive classrooms. And a Michigan Department of Education study, after reporting on research data showing a strong trend toward improved student outcomes in inclusive settings, adds, "One must seriously question the efficacy of spending ever-increasing sums of money to maintain dual systems." **EP**

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The NCERI BULLETIN *is available at no cost. The NCERI 1995* STUDY OF INCLUSIVE EDUCATION AND EDUCATIONAL RESTRUCTURING *may be purchased for $15, prepaid. Both are available from NCERI, The Graduate School and University Center, The City University of New York, 33 W. 42nd St., Rm. 1530, New York, NY 10036.*

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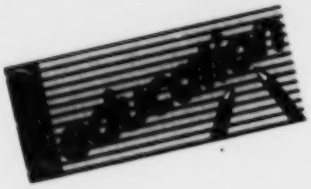

The Law and Inclusion

by Barbara Ebenstein

The Individuals with Disabilities Education Act (IDEA) encourages school districts to educate children with disabilities in regular classrooms. The IDEA uses the term "least restrictive environment," meaning that "to the maximum extent appropriate," children with disabilities should be educated with children who do not have disabilities, and that "special classes, separate schooling or other removal of children with disabilities from the regular educational environment, occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

Unfortunately, this language leaves many questions unanswered: When is inclusion appropriate? What supplementary aids and services are reasonable in a cost-conscious school district? When can one conclude that inclusion cannot be achieved satisfactorily? And whose satisfaction are we talking about? Parents and school districts often disagree on these points.

When parents and school districts disagree

Parents who do not agree with the school district regarding a child's evaluation, classroom placement or IEP (Individual Education Plan) can turn to legally-established due process procedures referred to as "administrative remedies." The first of these is an "impartial hearing," which is like a miniature trial in which both sides present witnesses and evidence, including reports of the child's past classroom experiences, to a hearing officer. The hearing officer acts as judge and renders a written decision.

Either side—the school district or the parents—can appeal this decision to the review officer in the state's department of education. After reviewing the electronic or written record of the hearing, the evidence that was presented and the decision of the hearing officer, the state review officer will issue a written decision about the case.

This decision signals the end of "administrative remedies." Most grievances are resolved by this point. However, if the parents or representatives of the school district remain dissatisfied, they can seek judicial review of the case in the federal courts.

This process begins by filing the case in federal district court, which holds a full trial and renders a decision.

Next, either side may appeal to the federal circuit court for the region that includes their state or U.S. territory (see sidebar, page 42). The circuit court will review the transcript of the district court trial, the evidence presented and the decision rendered. Lawyers for both sides submit written briefs (documents summarizing the issues and pertinent laws) and present oral arguments. After a decision is rendered, the case may be appealed to the U.S. Supreme Court, however, very few such cases are accepted for review.

Because the U.S. Supreme Court has not directly addressed the issue of inclusion, each federal circuit court must set its own criteria for determining when inclusion is appropriate. A circuit court decision sets a precedent to be followed in the states within the court's jurisdiction. Lower courts in jurisdictions where there has been no circuit court precedent are influenced by opinions from other jurisdictions.

To know the criteria a school district should use to determine whether inclusion is appropriate for a particular child, one must be familiar with the precedent followed by the federal circuit court in that jurisdiction. This is important information for parents to have—whether they want their child included or are advocating for a more segregated placement.

"Mainstreaming" and academics

In 1980, the U.S. Supreme Court reviewed an IDEA case brought by the parents of Amy Rowley, an eight-year-old who was deaf, and who attended her local elementary school. Amy's parents wanted a sign language interpreter in Amy's classroom. Although inclusion was not at issue in this case, the Court's decision stated that a child with a disability, who was being educated in a

Fox Chapel Area High School, Pittsburgh, Pennsylvania

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When you walk into classrooms at Fox Chapel Area High School, you can expect to see students moving in and out of learning groups and to hear teachers coaching and giving feedback to the students. But don't expect to be able to tell which students and teachers might be labeled "special education."

The divisions between regular and special education aren't obvious here. Instead of special education, we provide educational support. Support teachers—formerly called special education teachers—team up with content-area teachers each day to provide instruction to groups of students with diverse learning abilities. In co-taught classes, support is available to any student who needs it.

Here is what support at Fox Chapel looks like: In a social studies class you may see a cooperative learning group clustered in a corner working on a map project. A second teacher is going over yesterday's homework with students seated around a table. As you walk into a math class, you may see several students working on a computer-assisted math assignment, while next door, another math teacher is working with four students from the same class, providing a mini-lesson on measuring volume.

Through team-teaching and adapted instruction—including adapted study materials and testing—Fox Chapel Area High School has succeeded in creating a comprehensive inclusion program that addresses the diverse needs of all its students.

Nominated by Lynne Porterfield, coordinator of special education

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regular classroom, would be expected to work on grade level and progress from grade to grade with the rest of the class. The *Rowley* case validated the existence of two separate educational systems—one segregated system and one regular system in which children with disabilities who could perform on grade level were mainstreamed. This meant that most children with disabilities were placed in segregated classes, and "mainstreamed" only for music, art or physical education.

Relaxing academic standards

In 1989, an important circuit court case relaxed the requirement that a child with a disability must be able to work on grade level to be included in a regular classroom. The parents of Daniel R., a six-year-old with Down syndrome, wanted their son placed in a regular classroom in Texas. The Fifth Circuit Court ruled that there could be some modification of the curriculum to accommodate Daniel's special needs. The court stated, "We cannot deny the child access to regular education simply because his educational achievement lags behind that of his classmates," but added that "mainstreaming would be pointless if we forced instructors to modify the regular education curriculum to the extent that the handicapped child is not required to learn any of the skills normally taught in regular education." This court envisioned mainstreaming as appropriate for children who could master at least *some* of the regular curriculum.

As part of the *Daniel R.* decision, the court developed a "test" still widely used to determine "the least restrictive environment" appropriate for a particular child. This test requires a school district to weigh four factors in determining whether a child can receive an appropriate education in a regular classroom: 1) the educational benefit to the child, 2) the non-academic benefits to the child, 3) the potential disruption to the classroom and 4) the cost of the placement with all necessary supplementary aids and services. The school district must make reasonable efforts to accommodate the child in a regular classroom—not "mere token gestures"—but if the child cannot be placed in a regular classroom, the school district should integrate the child into regular school activities whenever possible.

In this case, evidence showed that Daniel was unable to master any part of the curriculum, and that his need for constant attention disrupted the class. The court ultimately permitted Daniel to be placed in a self-contained special education class. The *Daniel R.* test sets a precedent that *must* be followed only in Texas, Louisiana and Mississippi, however, it has influenced cases in other jurisdictions.

One such case was brought by the parents of Christy Greer, a 10-year-old with Down syndrome. Applying the *Daniel R.* test, the Eleventh Circuit Court decided that Christy's school district in Georgia had not made a sincere effort to accommodate her in a regular classroom. The court ruled that the district must consider *all* supplementary aids, services and curriculum modifications that could facilitate Christy's inclusion. Christy's school district was ordered to place her in a regular classroom. The Greer case sets a precedent that must be followed in Alabama, Georgia and Florida.

Inclusion for all?

More recent cases have encouraged the inclusion of children with disabilities even if they cannot master *any* grade-appropriate curriculum. For many people, this differentiates "mainstreaming" from "inclusion." The parents of Rafael Oberti, an eight-year-old child with Down syndrome, wanted their son fully included in a regular classroom in New Jersey. Due to the severity of Rafael's disability and his history of disruptive behavior, the school district proposed placement in a self-contained classroom. In a lengthy trial, educational experts discussed a variety of accommodations including a resource room, curriculum modification and "parallel instruction," which would permit Rafael to work on an activity beneficial to him while the rest of the class worked on a different activity.

Following the *Daniel R.* test, the court ordered Rafael's inclusion without

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Steinmetz Academic Center, Chicago, Illinois

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Mrs. Jackie Williams once feared a phone call from the administration of Chicago's Steinmetz Academic Center suggesting she find another placement for her son, Carl, because of his disabilities. That call never came. Instead, she celebrated her son's success after his return from the state capitol, where he and other students from Steinmetz had presented a play focusing on the gifts and talents of a diverse school population in an urban milieu!

The following factors have led to the success of the teaching and learning process at Steinmetz:

- **An "all-means-all" commitment from the principal, Dr. Constantine Kiamos; assistant principal, Dr. Arthur Tarvardinan and Steinmetz staff.**
- **A collaborative team approach with input from parents, staff and central office support staff.**
- **An absence of "road blocking" behaviors and attitudes: the entire team focuses on opportunities rather than limitations.**
- **A proactive parent advocacy group focusing on the needs of children.**

"Birthday boy" Curtis Mitchell (left), a student at Steinmetz High School, gets a squeeze from a pal.

Because Steinmetz Academic Center values flexibility and has never believed in maintaining the status quo for its own sake, the school can adequately address the needs of its students as they present themselves in the proverbial "teachable moment."

Nominated by Charlene Green, associate superintendent for special education and Greg Stricklerpoe, senior adviser for inclusive schools

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considering the cost of accommodations, because neither side raised the issue. The *Oberti* case is important not only because it provides a precedent in New Jersey, Pennsylvania and Delaware, but also because the U.S. Department of Education based its position paper on inclusion on this case.

In a similar case, the parents of Rachel Holland, a nine-year-old girl with a developmental disability and a tested IQ of 44, wanted her included in a regular classroom in California. The Ninth Circuit Court, applying the *Daniel R.* test, determined that Rachel should attend a regular classroom with additional services. Unlike *Oberti*, the court considering *Holland* was asked to consider the cost of including Rachel, and found that the Sacramento school district had exaggerated these costs.

Rachel's school district also asked the court to consider the extent to which the curriculum would have to be modified for Rachel. However, the court found that the need for curriculum modification is implied by the IDEA. The *Holland* decision sets a precedent that must be followed by lower courts in Alaska, Arizona, California, Hawaii, Idaho, Nevada, Oregon, Utah, Washington and the U.S. territories of Guam and the Northern Mariana Islands.

Variation in inclusion criteria

As discussed above, four federal circuit courts—the Third, Fifth, Ninth and Eleventh Circuits—have established inclusion criteria based on the *Daniel R.* test. Most school districts in the 21 states and territories within these four circuit court jurisdictions use the *Daniel R.* test as applied in *Oberti* and *Holland*.

The Sixth Circuit Court uses a different standard based on an earlier case in which a school district in Ohio recommended that Neill Roncker, a nine-year-old with severe mental retardation, be placed in a special county school. His parents, however, wanted Neill educated in a self-contained class in a regular school where he could have opportunities—during lunch and recess—for interaction with peers who did not have disabilities. The school district contended that any small benefits Neill would receive from this "mainstreaming," would be outweighed by the academic benefits of the special school.

The court's decision stated that if placement in a segregated facility is considered superior for a particular child, the school district must determine whether those services that make that placement superior could be provided in a regular school. If so, the regular school is the appropriate placement. In such cases, school districts must consider the following factors: the benefits derived from services that cannot be provided in a regular setting, the disruption caused by inclusion of the child and cost. The Fourth and Eighth Circuit Courts also have applied the *Roncker* test.

Conclusions

Inclusion is merging the two previously separate educational systems mentioned by the U.S. Supreme Court in the *Rowley* case into one comprehensive system for most children. Determining the appropriate placement for a particular child always involves an analysis of his or her unique abilities, disabilities and special needs. Potential benefits to the child are balanced against the potential burden to the school district. The outcome depends on the specific facts of each case, and often depends on the child's age and disability. Courts have ordered the inclusion of young children with Down syndrome and other developmental disabilities, while

Syracuse City School District, Syracuse, New York

1995 EDUCATION AWARD

The Syracuse City School District believes that team-teaching is the best way to offer appropriate supports to students in inclusive classrooms. Each inclusive classroom is staffed with a regular education teacher, a special education teacher and a special education teaching assistant. Each class includes six to eight students with special needs, with approximately 25 "typical" students. No entrance criteria or disability category excludes students from inclusive classrooms.

Currently, 50 elementary classrooms in 13 different schools are full-day inclusive settings. Two middle schools have inclusion teams—comprised of about 110 typical students and eight to 12 students with special needs—at the seventh- and eighth-grade levels. One high school in Syracuse has offered an inclusive program for three years to approximately 85 students who would have been assigned to self-contained classrooms.

For students at Salem Hyde Elementary School, part of the Syracuse City School District, "sitting in the corner" means an opportunity to learn.

I was visiting this high school one day when a student with special needs, who had been in the inclusive program for four weeks, stopped me and said, "Now that I'm not in special education anymore, do I still have to ride the yellow school bus to school?" In Syracuse high schools, students with special needs, who can't handle public transportation, ride traditional yellow school buses. Within the last four weeks, this student's self-esteem had risen to such a degree that he no longer considered himself a special education student. Of course, I immediately took his name off the yellow bus route and made sure he was given a bus pass.

Nominated by Edward Erwin, director of special education

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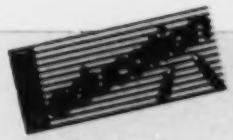
older children and those with high management needs are usually placed in segregated settings.

Some school districts are now experimenting with full inclusion for all children with disabilities. Done properly, inclusion should cost a school district as much as self-contained special education, but some districts try to save money by including children without providing sufficient supplementary aids and services. Some parents of included children are dissatisfied with the training of regular classroom teachers and the attitudes of other children. Parents of more than 300 children with learning disabilities in Maryland brought suit to prevent the inclusion of their children. The court dismissed the case because the parents had not yet exhausted their administrative remedies. But in the future, more parents may properly file "reverse-inclusion" cases, in which they ask to have their children placed in more segregated settings while their school districts propose full inclusion. These parents will argue that although inclusion is the "least restrictive environment," it does not meet the IDEA's requirement of an "appropriate" education for their children.

Inclusion is an emotionally charged issue for parents. It touches on the severity of the child's disability, as well as the child's future assimilation into the community. One mother told me, "my son used to be disabled; now, he is included." This statement is either a tragic misconception of the nature of disability or a profound statement of the potential of inclusion. **EP**

Barbara J. Ebenstein is a partner in the law offices of Ebenstein & Ebenstein in New York City. She lives with her husband, Dr. John E. Handelsman, and their three daughters, Sarah, 14, Leanne, 12, and Risa, 9, who has a neurological impairment.



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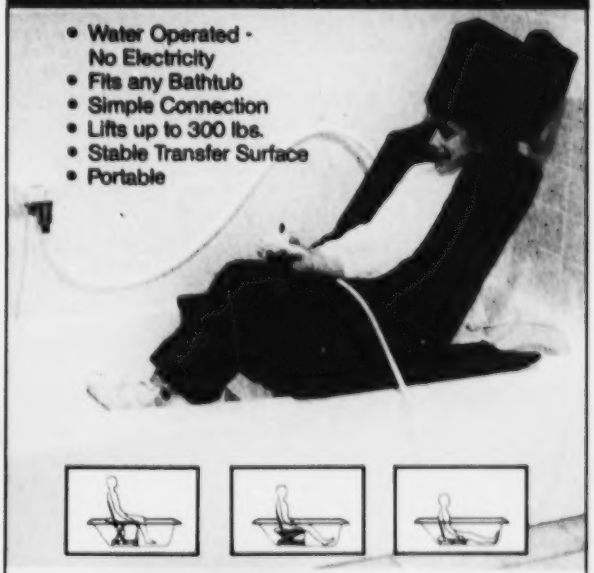

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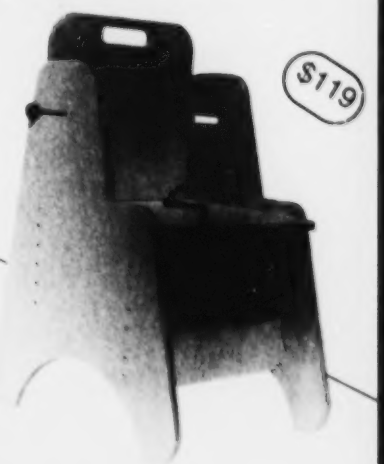

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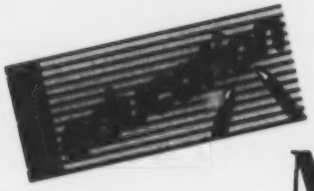

Making a Good Law Better

IDEA proposal stresses greater parental involvement and student inclusion

by Judith E. Heumann

This past summer, the Clinton administration introduced to Congress a proposal for reauthorization of the Individuals with Disabilities Education Act (IDEA). This marks the first substantial revision to the law since 1975, when Congress enacted Public Law 94-142, the basis of IDEA.

The proposal was the result of a year and a half of careful study, thorough reexamination and intense analysis by my staff at the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS). During this process, we consulted with some 3,000 educators and parents of students with disabilities.

The proposal demonstrates our commitment to ensuring that equality of educational opportunity is more than a rhetorical slogan. We want it to become a daily reality for every student in America—those with disabilities and those without. As Secretary of Education Richard Riley says, "America cannot afford to waste the talents, knowledge or skills of a single individual."

The IDEA proposal is a key part of President Clinton's package of national disability policies, based on "inclusion, not exclusion; independence, not dependence; and on empowerment, not paternalism."

Closing the gap

IDEA has proven to be an extremely effective law. A recent Louis Harris survey report states that "...largely due to the IDEA, the gap in education [between students with disabilities and those without] is beginning to close."

Are we satisfied? No!

Too many students with disabilities are still failing courses and dropping out of school. Their enrollment in post-secondary education is low, and too many are leaving school not fully prepared for employment and independent living.

I believe we should continually raise our expectations for special education. We can and should adjust the IDEA to meet the changing needs of the 21st century.

Strengthening the IEP process

The most important parts of our IDEA reauthorization proposal are changes intended to strengthen the IEP (Individual Education Plan) process and to encourage the early and continuous involvement of parents. Under our proposal, students with disabilities are to be taught the same general curriculum as students without disabilities, or parents must be told why not. We want students with disabilities to be able to meet the same challenging standards established by states and communities for children without disabilities.

Jefferson County Public Schools, Jefferson County, Alabama

1995 EDUCATION AWARD

Inclusion is a "hot topic" in special education, and rightly so. Most discussions about inclusion, however, focus on the school—team teaching, use of para-professionals, modifications in the regular classroom.

But isn't the least restrictive environment truly found only in the real world—the community? The Jefferson County School System embraces this broader view of inclusion. Junior and senior high school students with moderate to severe disabilities are beginning to participate in community based instruction (CBI), in which students leave the school setting, become active participants in their community and learn to perform real-world skills. Successfully performing skills accomplishes many goals of inclusion by improving academic achievement, self-esteem, parental expectations and community acceptance of students with disabilities.

Jefferson County's comprehensive view of inclusion includes work experience in the community. In this photo, student Jimbo Karr works in a local laundry.

CBI not only teaches our students with disabilities to function in the real world; it also teaches the real world about people with disabilities. The community comes to view students with disabilities as prospective employees, and people willingly offer their businesses as work assessment sites.

With an inclusionary view of inclusion, we as educators will be more effective in offering students with disabilities opportunities to enhance their quality of life.

Nominated by Penny Ray, supervisor of exceptional education

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Six principles

Our proposed IDEA improvements are based on six key principles, with strategies to implement each:

• *Align IDEA with state and local education reform efforts so students with disabilities can also benefit.* Connecting IDEA programs with educational improvements occurring in schools around the nation would help ensure that all children are included in school improvement activities. "Special education" would be seen as supports and services rather than separate programs and places.

• *Improve results for students with disabilities through higher expectations and access to the general curriculum, in the least restrictive environment.* A child's IEP would focus on his or her participation in the general curriculum and methods of evaluating his or her progress and educational program.

As before, members of the IEP team would include the child's parents and special education teacher. In addition, our proposal would mandate the participation of at least one regular education teacher, if the child is now or is likely to be in a regular classroom. Parental input would be an important part of developing the IEP and determining measurable annual objectives.

Importantly, IDEA would now require that parents receive reports on a child's progress on a regular basis—by such means as report cards—at least as often as reports are issued to the parents of students without disabilities in the school. These reports will allow parents to judge the success of the child's IEP and determine whether modifications are needed.

The IEP would have a greater focus on what is necessary to ensure successful inclusion—the services and supports needed for the child to learn to high standards, in the same curriculum used for all children, to the maximum extent possible. It would also describe the special education, related services and program modifications a child needs to meet annual IEP objectives, to participate in the general curriculum and to take part in extracurricular activities. Moreover, it would justify the extent—if any—to which a child will not be educated with students without disabilities.

A critical new addition to IDEA would be that children with disabilities, with few exceptions, would participate in state and district-wide assessments. Recognizing that a small number of students with significant cognitive disabilities cannot be included in regular assessments, the IDEA would require alternative assessments in order to measure the performance of these students. Results for all students with disabilities, such as state assessments, would be publicly reported, thus ensuring more accountability for educational results.

Transition planning would begin when a child turns 14. This planning would consider the course of study and supports needed to move toward post-secondary education, employment or other meaningful activities.

• *Address individual needs.* A child's initial evaluation and three-year reevaluation would be more likely to include information to help parents and teachers judge the effectiveness of various teaching methods. Once it is determined that a child has a disability, the currently required reevaluation would no longer have to include a full battery of tests to determine whether the child continues to have a disability, as long as both the parents and the school agree these tests are unnecessary.

The current procedure of making educational decisions based solely on a child's disability category is contrary to what research shows and parents know—that each child has unique needs, regardless of his or her disability category. To promote eligibility determinations that focus on educational needs, states would be allowed to use eligibility criteria that are less categorical. This means that criteria used to determine eligibility for special education could focus more on needs and less on diagnostic labels, while ensuring that all students who are currently eligible, remain eligible. Of course, parents would still have the right to challenge eligibility decisions made by school districts.

Changes in the IDEA funding formula would encourage states to do early intervention and prereferral activities. It would be easier for a child's school to provide special education services in the regular classroom because the excessive paperwork now required to track the use of IDEA funds would be eliminated. And the elimination of "labels" would discourage the over-identification of children for special education, helping schools better serve all students.

• *Provide families and teachers—those closest to students—with the knowledge and training to effectively support students' learning.* Too often today, parents get notices that are too long and too full of "legalese." To help parents understand the issues included in the notices, we propose improvements to the notice requirement to ensure that parents get better, more useful information. Importantly, parents would be part of the child's placement team, a right not previously mandated by federal law. Thus, they would have a right to participate in this critical decision about their child's education in those states that do not now provide for their participation.

WE CAN AND SHOULD ADJUST THE IDEA TO MEET THE CHANGING NEEDS OF THE 21ST CENTURY.

In addition, in order to help resolve disputes in a "parent-friendly" manner, states would be required to offer parents mediation as an option for resolving any complaints parents might have with their child's school. However, parents would continue to have the option to request a hearing.

We would promote state and community partnerships to meet the educational, health, mental health and social service needs of children and their families.

The Department of Education is an

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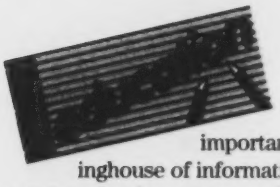

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important clearinghouse of information about practices that have proven effective for families, schools and communities. To help make the best information about what works available, we would make a coordinated effort to do research on key issues and make information available to those who want it.

We also know that trained teachers and other professionals are vital to student success. Therefore, the federal government would make funds available to states to develop statewide plans for professional development. This would assure that those who work with children with disabilities would be appropriately trained. To help parents support their children's learning and understanding, a parent training and information center would be required in every state.

• *Focus resources on teaching and learning.* Because unnecessary paperwork would be eliminated, teachers and administrators could focus more effectively on educational activities.

Schools would have greater ability to maintain safe and disciplined classrooms. A student who brings a firearm or other dangerous weapon to school could be moved to an alternative setting. Also, hearing officers would be permitted to place in an alternative setting students who are substantially likely to injure themselves or others. These alternative placements could last up to 45 days, during which time the IEP team would consider appropriate services and placement for the student.

• *Strengthen early intervention services.* Infants and toddlers at risk of developmental delay would be more likely to receive early intervention services because states would have the option of providing service coordination only to these children. As a result of the recommendations of a panel of experts, less variation in the definition of "developmentally delayed" could exist from state to state.

Every child is different

I believe our society should provide the resources necessary to allow each individual child—those with and without disabilities—to succeed in school and to prepare for a productive, fulfilling life. The specific resources needed, and the combination in which the resources are needed, will be different for each child, because each child is different. **EP**

Judy Heumann is Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS) of the U.S. Department of Education.

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1995 Exceptional Parent Education Awards: Honorable Mention

1995 Education Award

The Betsy Ross dance troupe gave a special performance based on Disney's "The Lion King." Troupe member Kelle, 12, (front right) has Down syndrome.

• **Betsy Ross School, Anaheim, California:** Children in special education classes are involved in all educational and after-school activities, including a pageantry troop, dramatic productions and an ongoing Special Olympics training program. Sixth-grade students with disabilities are looking forward to attending a week-long science camp this fall with sixth-graders who do not have disabilities. *Nominated by Larry Herschler, special education teacher.*

• **Daniel Webster Middle School, Waukegan, Illinois:** Daniel Webster Middle School has an in-class model of service delivery for students with learning disabilities (LD) included in regular classrooms. An aide helps each student meet the demands of the regular class, and resource periods offer additional support. *Nominated by Will Guilianelli, coordinator of special education for learning disabilities.*

• **Jenks Public Schools, Tulsa, Oklahoma:** Each school in the Jenks district has an inclusion team consisting of staff representing regular and special education. "Circle of friends" clubs and peer-tutor programs promote student understanding and acceptance of individual differences. *Nominated by Janet Ellsworth, director of special education.*

• **L.P. Brown Elementary, Olympia, Washington:** Children with disabilities participate fully in age-appropriate classrooms and within the school community. General and special education teachers provide learning experiences that build on each child's strengths and needs. *Nominated by Stillman W. Wood, assistant superintendent and Paula Akerlund, director of special services.*

Miller Middle School teachers Marilyn Dysart (left) and Karen Allen (right) help students build molecular models. Teaching pairs are an important part of Miller Middle School's "cooperative classes."

• **Miller Middle School, Marshalltown, Iowa:** Miller Middle School has more than 40 "cooperative" classes offering special education services in a regular classrooms. Complimenting cooperative classes, Miller Middle School has an education center where special education professionals offer homework assistance. *Nominated by Brad Clement, principal.*

continued on page 48

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Circle #262

1995 EXCEPTIONAL PARENT Education Awards: Honorable Mention

1995 EDUCATION AWARD

Stephen Rogers, 8, a student with Down syndrome, spends his recess at Oak Mountain Elementary "hanging around" with friends.

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• **Oak Mountain Elementary School, Shelby County, Alabama:** As part of an inclusive-education pilot program, 67 students with disabilities were fully included in regular classrooms. The program's success led to Oak Mountain Elementary's selection as a state model demonstration site for inclusive education. *Nominated by Kathy Snyder, early childhood special education program specialist.*

• **Park School, Evanston, Illinois:** The curriculum at this center-based school emphasizes oft-overlooked areas such as home living, social interaction, mobility training and money management; the school uses vocational training to develop skills for future employment. A job program places students into community job-training positions. *Nominated by Judy Alonso, president, Park School PTA.*

Students in a Park School home living course learn about various components involved in house management.

• **Signal Hill Elementary School, Voorhees, New Jersey:** Signal Hill Elementary enabled Crystal, an 11-year-old girl with Werdnig-Hoffman disease who lives at Voorhees Pediatric Facility, to progress academically and socially. Crystal, accompanied by a full-time nurse, changed classes with her peers for music and gym and received special education for other classes, including reading and math. *Nominated by Lisa Baldwin Piccolo, Voorhees Pediatric Facility social work coordinator.*

• **Wendell Elementary, Wendell, Idaho:** This early childhood educational program provides services to three- to five-year-old children with developmental delays. Integration opportunities are provided by bringing children without disabilities into the preschool setting. *Nominated by Margo Sears, parent, and Brenda Hall, pre-school teacher.*

Twelve-year-old Crystal accepts her graduation certificate from Bernadette Gorman, special education teacher at Signal Elementary School.

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In Defense of Educational Choice

On April 14, 1977, Jim and Connie Roberts learned that their youngest daughter, 18-month-old Katie, was profoundly deaf. Connie remembers the date clearly, because Jim, an accountant, took the day off so he could be there when Katie was tested. Connie laughs about that detail now, "I think the only legitimate reason for a CPA to take time off the day before tax deadline is a funeral—preferably their own."

Like other parents of a child with a newly-diagnosed disability, Jim and Connie started looking for answers. They were given plenty of "solutions," Connie recalls, "each in conflict with the other. All-or-nothing philosophies, messages that said, 'Follow us, or your child is doomed to failure.'"

Below: During her senior year at the Model Secondary School for the Deaf (MSSD), Katie toured the U.S. and Europe with MSSD's performing arts "road show troupe."

Above: Katie Roberts, 10, spent fourth grade in a regular classroom with an interpreter at the Oscar Howe Elementary School in Sioux Falls, South Dakota.

In response, Jim and Connie decided to come up with their own goals for Katie, goals that could be used to evaluate potential educational methods and placements. Their list of objectives included positive self-esteem, responsibility, independence, social skills, becoming a life-long learner. "Not exactly IEP goals," says Connie, but "life goals" that would require a strong academic program.

By the time Katie was ready for kindergarten, her parents realized that no single available program could meet all her academic and social needs. Their solution was to work out an arrangement that allowed five-year-old Katie to spend half-days in a classroom at the South Dakota School for the Deaf (SDSD), and half-days in a regular kindergarten classroom with an interpreter—"the first classroom interpreter in the Sioux Falls public schools," Connie adds.

Katie's educational program continued to change with her needs. She was fully mainstreamed for most of elementary and junior high school; in high school, she returned to a "split-day" program, dividing her time between SDSD and the same Catholic school her older siblings attended. To have a more complete social life, she spent school weeks living in the dorm at the school for the deaf. Then, in the middle of her sophomore year, Katie transferred to the Model Secondary School for the Deaf, on the campus of Gallaudet University in Washington, DC (where she now attends college). "Allowing that move was difficult," says Connie, "but we realized we could not create an environment for her here that could meet all her social, emotional and academic needs."

"More than we could provide at home"

Kimberly Donovan, 22, who has mild mental retardation and developmental aphasia, has been a residential student at the Cardinal Cushing School and Training Center, a program of St. Coletta's of Massachusetts, since 1987. Before that, she attended several public school programs. Her father, Jerry, says, "I know the trend today is to include all kids in the regular classroom. That's fine for some students—but not Kim. She needed the kind of individual attention she couldn't get in a regular classroom."

Cardinal Cushing provided an excellent academic program, says Kimberly's mother, Jackie, who is particularly proud that Kim defied "expert" predictions and learned to read. But the residential program had other benefits, too. Through participation in Girl Scouts, school plays, special-interest clubs and cheerleading, Kim's social skills grew tremendously. "When Kim first entered the school," Jackie explains, "she related only to adults. Over the years, she has learned to communicate with and relate to her peers. She's made friends. Those 'fun' activities at school gave

continued on page 52

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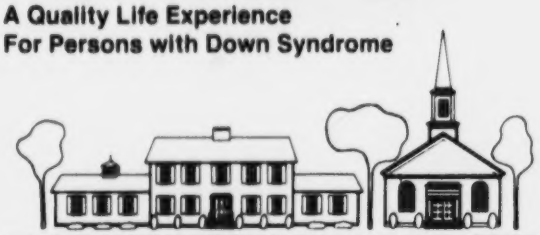

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Circle #204

continued from page 50

her so much more than we could have provided at home."

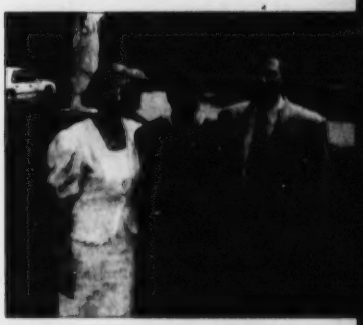
Defining "LRE"

The Donovan and Roberts families worry that advocates of a one-size-fits-all approach to education will rob today's parents of the range of placement options their children enjoyed.

These concerns are echoed by attorney Lawrence Siegel, author of *Least Restrictive Environment: The Paradox of Inclusion* (LRP Publications, PO Box 980, Horsham, PA 19044-0980; 800/341-7874, ext. 275; $32, incl. shipping). "The IDEA [Individuals with Disabilities Education Act] is a good law, basically," Siegel says, "but it has two problems. First, it calls for placement in the 'least restrictive environment'—or 'LRE'—but at the same time, requires the provision of an 'appropriate education.' Courts have recognized that the LRE requirement is sometimes in conflict with the 'appropriate' requirement.

"Secondly, the LRE requirement itself is very confusing. Many people think of LRE as a *place*, when, in fact, LRE is a *process*. Courts have stated that the regular classroom is the LRE for some children; but in other cases, they have been equally clear that a state school can be the LRE."

Siegel has represented parents who wanted their children included, as well as those who wanted their children moved from regular classrooms to more segregated settings. "I feel very strongly that we need to look at individual children and their individual needs," he says. "It is ironic that the inclusion movement came about because school systems were making generic decisions about placement—keeping kids out of regular classrooms based solely on their disability category. Inclusion advocates were upset about that—and rightfully so. But now, when some say that *all* children with disabilities should be in regular classrooms, they are doing the same thing to others."



Kimberly Donovan, 22, celebrated her June 1995 graduation from Cardinal Cushing School with her parents, Jackie (left) and Jerry.

A focus on individual needs

In the following pages, a number of parents share stories about the educational choices they have made for their children. Running through these very diverse stories are several common threads. One is a belief that placement decisions should be based on the individual child, and his or her unique needs. Another is a profound respect for the choices of others—although these parents have made very different choices, each is careful to avoid making pronouncements about the "right choice" for other parents and children.

Connie Roberts probably speaks for many when she says, "There are no perfect programs, just different options. We can't look at any option as right or wrong; instead, we need to ask how a particular program can meet the needs of children. The program that works best is the one that works best for *your* child."

—Kim Schive

Kim Schive is associate editor of EXCEPTIONAL PARENT.

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Readers Talk About: EDUCATIONAL CHOICES

Where Do We Go From Here?

Shortly after Sheila was born, we heard about a conference on inclusion. We went; we listened; we jumped on the bandwagon. It became very important to us that our child with Down syndrome be raised in the same world where the rest of us reside.

We made sure Sheila spent her preschool years around "typical" children. She attended the Rainbow Express Learning Company, the same nursery school as her older sister—"Of course, we'll take her," director Sandi Hughes told me. "This is one battle you will not have to fight." The school made some accommodations to make it work, but work it did.

Seven-year-old Sheila Holroyd (right) dressed as a fortune teller for the first-grade Halloween party in October 1994.

By the time Sheila turned four, we had established a track record demonstrating she could be successful in an inclusive setting with proper supports. As a result, our school district was willing to try half-days in the regular classroom with an aide and consulting teacher.

Sheila's first year of kindergarten had its ups and downs. The consulting teacher argued with me constantly; she felt Sheila belonged in a segregated setting. The speech therapist, who told me she had not gone into speech pathology to work with "kids like Sheila," presented another problem. At many of our monthly team meetings she would make comments about Sheila's personality ("She's lazy") or cognitive abilities ("After all, she *is* severely retarded").

I alternated between blinding rage and a depression so deep I would cry for days. By mid-year, when Sheila's classroom teacher went on maternity leave and her aide also left, I had to ask if this placement was the right thing.

But the second half of the year was better. The new classroom teacher happened to have a background in special education, and Sheila's new aide adored her. With adequate support in the classroom, I was no longer as worried.

The following year, not yet ready to sit quietly for extended periods as required in first grade, Sheila, now 6, repeated kindergarten. With a new consulting teacher, almost everything went smoothly—everything except speech therapy. And unfortunately, speech therapy was becoming more and more important. Sheila, an extremely social child, was still essentially nonverbal and becoming increasingly frustrated.

Should we stop "doing inclusion" because of staffing problems, or should we hold firm to our belief that we all belong together? My husband, Forrest, maintained that holding fast to the ideal was important. I waivered. If only I could convince myself that inclusion is always the best option. "We don't hesitate to create special programs for gifted children," I thought. "Why do we insist an inclusive setting is best for all children with disabilities?"

We decided to "hang in there," and Sheila moved on to first grade. This past year—spent in a first-grade classroom of 28 students—was especially tough. Sheila started demonstrating inappropriate behavior, such as hitting other children. Several teachers recommended having her tested for attention deficit hyperactivity disorder (ADHD), but I was reluctant. Sheila really didn't need another label.

Finally, I discussed it with her pediatrician. After testing, Sheila had a new label and a prescription for medication. Her behavior improved, but she was still easily distracted. We were asked to consider having her spend one period a day in the resource room. Reluctantly we agreed, but we can read the writing on the wall—45 minutes this year; next year, what? Two hours?

But this past year also brought us a new speech therapist and a small miracle—Sheila is talking! It began with one or two new words a day. Now, there are so many I cannot keep track of them. Mrs. Chico, the speech therapist, uses signs and the manual alphabet to cue Sheila's speech. She shows Sheila how to make her mouth form the right shapes to make sounds. If the rest of Sheila's program could get

READERS TALK ABOUT

We invite you to contribute to the discussion in future issues of Exceptional Parent. In upcoming months, readers will be talking about:

- Grandparents/extended family (December; deadline Oct.1,1995)
- Early Intervention (February; deadline Dec. 1, 1995
- Camps (March; deadline Jan. 1, 1996)
- Vacations (April; deadline Feb. 1, 1996)

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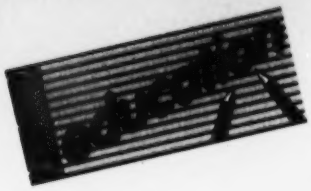

its act together, I would keep Sheila in this school forever—just to work with Mrs. Chico.

We continue trying to make inclusion work. As Sheila begins second grade, I try not to lose sleep over circumstances that are out of my control. I don't know that we could find a school district as willing to try as ours; we continue to hope they will somehow get it together. But we continue to explore other options.

Where do we go from here? What is best for Sheila? In the coming years, we know we will need to remain flexible so we can find the best ways to give Sheila all the skills she will need to have in the grown-up world.

—Nancy E. Holroyd
Duanesburg, New York

IF ONLY I COULD CONVINCE MYSELF THAT INCLUSION IS ALWAYS THE BEST OPTION.

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A Lesson From the "Inclusion People"

Kevin Haney, 3, attends the Lincoln School in Ontario, California.

I had enormous reservations about sending my child to school. For starters, I knew I did not want him attending a "school for the severely disabled." It wasn't that I preferred to have him integrated into a regular classroom, I just didn't want him labeled "retarded."

Kevin failed the test that would have made him eligible to attend a school for the "orthopedically disabled" and be integrated into regular classrooms. Nobody labeled him "retarded," but they did say he had "severe developmental delays" and suggested that he attend a school in our area that serves children with severe disabilities.

So, with some hesitation, I agreed. I visited the school; I observed the classroom; and yes, I tailed my son's bus to school—but only once.

I discovered I was happy. My son was going to a school where caring and educated people were knocking themselves out on a daily basis to provide Kevin and the other kids with a sound education and solid skills. The school was *alive* with laughter and brightness and progress. There was nothing depressing or dull or uninspiring about it. I loved the school! And more importantly, *Kevin* loved it.

And then I met the "Inclusion People." They are everywhere—I realize that now—but I met mine at a local workshop. They cornered me during the lunch break and grilled me about my son's educational placement. When I told them Kevin attends a special school, the lecture began—I obviously had *no clue* about the current thinking regarding education, and I was about to have a lesson. What I learned was astounding:

• *I hadn't realized that all three-year-old children needed the inclusion of my son in their program in order to become fully-functioning, sensitive, caring adults.* I thought I was responsible only to *my* son. I thought *his* needs were my first priority. Many times, I feel overwhelmed just providing for him; the needs of the entire three-year-old population of my community are more than I can handle.

• *I hadn't realized my son was unhappy being segregated from the rest of the preschool world.* I thought Kevin's smiles and coos meant he was happy. I thought the kicking and giggling he does only for his teacher meant he was filled with joy to be spending time with such a wonderful man.

• *I didn't know my son wasn't meeting his full potential at that school.* I thought a school that offers swimming, field trips, sing-alongs, sign language, parades, computers and the most up-to-date augmentative communication technology sounded fully prepared to bring out the best in my child. I thought that teaching my son to use a switch—despite his extreme physical and intellectual limitations—was a huge step in helping him reach his potential.

• *I didn't know I was so unhappy having my son attend a special school.* I thought I was comforted

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by the fact that his teacher knew *exactly* how to suction and position and g-tube feed my kid. I thought I enjoyed the monthly support group meetings led by the school's principal, on her own time. I thought I *loved* it that the staff was so taken with my son—that his teachers cuddle him and tell him jokes that make him laugh at the standing table.

• *I didn't realize I didn't have a choice.* Nobody had ever told me that choosing an appropriate educational environment for my son was *not my choice.* I thought all parents carefully weighed their choices and chose appropriately for their children. I did not realize I was sabotaging an entire educational movement by sending Kevin to a special school.

I was shocked. The "Inclusion People" were denouncing my choice—and an excellent one at that—sight unseen. I don't think it ever occurred to them that the population of people with disabilities is incredibly diverse, and that one program cannot possibly meet the needs of all. *Don't we still have room for choice?*

Our family is happy with Kevin's school; we are happy with the way it is serving his needs and the needs of other children with very severe disabilities. I believe all children with special needs deserve a program that meets their needs—either full inclusion, a special school, or something in-between. And most of all, I believe all children deserve a chance at the happiness Kevin displays at his school.

—Jill Chester-Haney
Ontario, California

■ ■ ■

A Varsity Letter for Inclusion

My son's graduation ceremony was a milestone for the whole family. As David marched across the stage, shook the principal's hand and then proceeded to envelope him in a giant hug, I felt an overwhelming rush of joy—and a huge sigh of relief. David's educational journey required tremendous effort from him and everyone else involved, but that effort reaped great rewards.

David proudly wears his letterman's jacket everywhere he goes — so, of course, he had to wear it for his senior picture!

David, who has fragile X syndrome, began his education in a totally segregated setting; recess and lunch provided his only exposure to "regular" kids. The professionals seemed convinced this was the best place to maximize his learning potential. It wasn't until David was in fifth grade that a new special education teacher suggested we try a more inclusive learning environment.

I'll admit I was frightened! What if it didn't work out? Didn't David face enough challenges already? Would other children tease him about his poor reading skills? And what about his hand flapping and hand biting? These behaviors often increased when he was in a stressful situation; how would the other kids react?

David was already the brunt of unkind comments and subtle abuses on the bus and playground. Very seldom did a day go by that another child did not greet him with, "Hey retard!" I wanted to protect him, to keep him safe. But I knew my husband and I would not always be there for David. If he was going to live independently after we were gone, he had to gain some of those important skills now. I swallowed my fears and agreed to try inclusion.

Initially, Dave was in the regular classroom only for a few periods each day, for subjects like art and gym. The following year, in sixth grade, he became a more active member of the class. He still ventured back to the resource room for reading and math, but the rest of his day was spent in the regular classroom.

It wasn't all smooth sailing. There were some initial problems, but slowly David began to change. His self-esteem increased. His behavior was not a problem. In fact, it was better in the regular classroom than in the self-contained setting.

And contrary to what many had predicted, David was learning. After years on the same level, his reading skills began increasing. He did well in social studies and science, showing great strength in general knowledge and awareness of current

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events, and often surprising teachers with his understanding of certain issues.

David's inclusion was not limited to the classroom. In seventh grade, he tried out for the school play and was given the part of a mummy in "Frankenstein Slept Here." On the night of the performance, my "shy, withdrawn, autistic-like" son slunk across the stage in a frightening mummy-like manner, remembered his four lines and showed us all what he could do when given the chance.

As a high school junior and senior, David was a member of the school's concert choir. He also served as football manager, receiving his varsity letter with the rest of the guys. He proudly wears his letterman's jacket everywhere he goes, even in the heat of summer. Participating in these activities increased his self-confidence, which carried over into other areas of his life.

As Susan McVicar, David's former special education teacher, says, "Every time David took a risk at school—whether it be talking with peers, presenting a report, handling the stress of the crowded hallways or participating in a school play—he was gaining life skills he could not have gotten had he remained in a self-contained setting."

I know there is no single "right way" for all children; each child is unique. But my experience prompts me to encourage other parents to consider the benefits of some degree of inclusion for their own child. I don't believe we can expect individuals with developmental disabilities to suddenly, upon completion of their schooling, be able to function in a society they have been separated from for years. If we truly believe each person is of value and has the right to "belong" in the community, how can we support education that segregates?

We'll never know where David would be today had he remained in a self-contained classroom. But I believe the David who hugs me good-bye as he heads off to work each morning is a happier, more independent, more self-confident young man than he would otherwise be, and a strong testimony to the positive benefits of an inclusive education.

—Jeannie Lancaster
Loveland, Colorado

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Circle #72

Amy's Experiment with Inclusion

"How can you send your child to a center-based school? She'll never learn how to behave unless she is around normal children!" I've heard this kind of accusatory statement from perfect strangers. I have no interest in arguing about educational philosophy; I just want the best possible education for my daughter.

Amy, 8, was born with multiple disabilities due to congenital cytomegalovirus (CMV). She has a profound hearing loss, profound mental retardation, a visual impairment and mild cerebral palsy. She does not vocalize and has no language. She wears ankle-foot orthotics (AFOs), and began walking at four years of age.

Amy's "education" began in a home-based program when she was six months old. Teachers came to our home to provide speech, physical and occupational therapies for a total of six hours a week. At two, Amy boarded a school bus for the first time, entering a specialized preschool program at a local school. Three years later, she began kindergarten at a center-based school.

During those years, she made amazing progress. The little girl who would throw herself down on the floor in the grocery store was now able to walk nicely with Mom. She learned that pulling out her hearing aid and putting it in her mouth would result in a time-out. And most importantly, she was becoming potty-trained. She wore regular panties all day without an accident. She was beginning to form some signs and was learning to eat with a spoon.

Amy made so much progress, in fact, that her teachers began urging me to transfer her to a self-contained classroom in a regular school. I visited the program they recommended and was quite impressed. Lessons were individualized, and children were able to spend some of their time in regular kindergarten or first-grade classes. With some hesitation I agreed to let Amy try this new school. The deciding factor was that she could continue to receive speech and hearing services from the same wonderful teacher she'd had in the center-based program.

The day before the 1994–95 school year was to start, I learned that this teacher had been transferred. To make matters worse, the experienced teacher I had observed during my visits the previous spring would not be teaching Amy's class; instead, her teacher was to be a recent college graduate with little experience.

I kept Amy home from school until I could meet with teachers and administrators from both schools. They all argued that Amy was "too smart" for the center school, that they would not be able to give her the stimulation she required, and that she would benefit from having "higher-functioning" and "regular" kids as role models. I was finally persuaded; so began Amy's experiment with inclusion.

Amy immediately regressed in all areas. We began to realize that the physical differences in the new classroom were having a profound impact on her learning and independence. The bathroom was not situated so a child could be watched from the classroom, and no large potty chair was available; as a result, Amy did not use the toilet all year. Strapped into a posture chair, she spent hours staring at the bright florescent lights instead of watching the teacher. Her ability and willingness to use language—signing or pictures—disappeared. Her focusing skills deteriorated. And I noticed a growing frustration when it came to accepting direction. Amy, with a 14-year-old brother and 11-year-old sister, was tired of being bossed around—both at home by her siblings and at school by her classmates!

We visited the center school again this spring. Many of the "higher-functioning" children have been moved to regular schools. None of the current students were as independently mobile as Amy, but some were at the same intellectual level. We think Amy would like to be a "big fish in a small pond" for a change—able to take the lead in group activities, able to push a friend's

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wheelchair, able to be with children more like herself. Though we met with some resistance from school officials, we've decided that Amy will return to the center-based school in the fall.

Although Amy's experiment with inclusion was a failure, we strongly believe parents should have a choice of programs. Inclusion is truly beneficial for some children, and it is important to have the resources to allow a child to join a regular class when appropriate. But it is equally important for children like Amy to have other options that can better meet their needs.

—Margaret Daigle
Falls Church, Virginia

WE THINK AMY WOULD LIKE TO BE A "BIG FISH IN A SMALL POND" FOR A CHANGE.

■ ■ ■

A Battle Well Worth Fighting

Three years ago, when my daughter was four years old, I had never heard the word "inclusion." But I did know Rachel used others as role models for speech and behavior, and it seemed only logical she would have more and better role models in a regular class.

Unfortunately, the "experts" in our school district believed in segregation. Rachel wasted her first year of school in a special day class for "speech-and-language-impaired" children. Her classmates had the same language difficulties as Rachel; some had behavior problems, too. All six were boys. Rachel spent that long year without another girl to play with; the only dolls in her classroom were the ones I donated. She didn't learn the language of play, because she never heard it.

At our next IEP meeting, the team was able to agree on most of Rachel's goals for the following year. But we reached an impasse when we started discussing the type of kindergarten class she should attend. Our school district dared us to file for due process; and we did. After several months of anguish, countless hours of discussion with our wonderful advocate and terrific attorney and more than eight hours of mediation, we finally had what we wanted—Rachel would attend the same school as her older brother, four blocks from our house. She would be fully included in a regular kindergarten class, with therapists coming into the classroom to work with her.

I wish I could say we all lived happily ever after, but that was not the case. We neglected to add one important item to our mediation agreement; we did not insist that the kindergarten teacher *want* the challenge of a child with disabilities.

Unfortunately, Rachel ended up with a teacher who didn't want the extra work and didn't want to be part of a team. Because Rachel was labeled "special ed," the classroom teacher took no responsibility for her education.

Socially, however, kindergarten was the best thing that ever happened to Rachel. She learned what to say during play, and she had *lots* of other little girls to play with. Thirty friends attended her birthday party; she'd never had friends to invite to a previous birthday celebration.

Before the start of first grade, I spoke at length to the first-grade teachers I wanted Rachel to have. I explained that inclusion meant more work for them, but that they would also learn a great deal. They had never had a student like Rachel before—actually, she was the first fully-included child in the school—but they were happy to give it a try. I crossed my fingers and hoped for the best.

Like kindergarten, first grade was a terrific social experience. The kids volunteered to be Rachel's partners in group activities. They protect-

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Rachel (seated) celebrated her seventh birthday surrounded by friends from her first-grade class.

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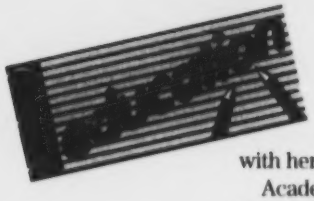

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ed her, they included her, they played with her and they liked her.

Academically, the year was at least as good. Rachel was treated like every other kid. When the other kids took weekly spelling tests using pencil and paper, Rachel used her computer. She learned to read better than some of her classmates—an accomplishment acknowledged by teachers and kids alike. Math was harder, but her teachers spent extra time helping her and trying new instructional methods. The teachers did not give up, and as a result, Rachel didn't either. Everyone in that classroom knew how hard Rachel worked. They respected her efforts and accomplishments and urged her to strive for higher goals. As a result, Rachel learned to do many things the "experts" said were impossible.

Dragging our school system into the 20th century has been a long, hard battle, but well worth the fight. I am reminded of that every time I look at my beautiful daughter's smile as she reads a story to her little brother.

—Margaret Simons
Beverly Hills, California

■ ■ ■

Never say "Never"

My daughter, Jamaica, was born totally blind due to anophthalmia, a condition in which the eyeballs fail to develop. From the time Jamaica was an infant, I was a believer in full integration. I was one of those parents who firmly states, "My child will never go to a residential school." But now, I say, "Never say 'never!'"

During a family vacation, the Millers—(clockwise from left) Jamaica, Tim, Lucky, Dixie and Diane—enjoy a fishing trip on the Gulf of Mexico.

Jamaica began her education in an integrated preschool and then attended the regular kindergarten class in our neighborhood school, receiving twice-a-week instruction from an itinerant vision specialist. On the other three days of the week, she had a personal aide in the classroom. Things went smoothly, and Jamaica developed many friendships with her classmates. But my husband and I still worried. Sighted children are exposed to print every day as they develop early literacy skills. We thought Jamaica needed more intensive exposure if she was going to learn to read and write Braille.

We moved to another school district, where Jamaica could receive daily resource instruction from a vision specialist, and still be in a regular classroom with her sighted peers. We also asked that Jamaica receive orientation-and-mobility instruction. The school district was willing to provide these services, but unable to find a qualified instructor. Finally, they contracted with someone to provide once-a-month instruction. Jamaica needed more, but we figured a little was better than none at all.

All things considered, Jamaica's educational program was more comprehensive than those provided to most children with visual impairments in the public schools. But despite all the efforts on her behalf, Jamaica fell further behind each year. She was frustrated, and her teachers were frustrated. At this point, we began to look at the intensive, specialized programs that would be available to her in a residential school for students with visual impairments.

In spite of the fact that I had said "never," I was glad to have that option when we needed it. But I certainly struggled with the prospect of sending Jamaica away from home for an entire year. A wise counselor suggested a trial placement for the last six weeks of the school year. Jamaica did well, and we re-enrolled her for the following year. The intensive specialized instruction was good for her academically, but we couldn't miss the rest of her childhood; we moved again, so she could live at home while attending the school as a day student.

For a while, we thought we'd found the best of both worlds. But Jamaica's school was in a

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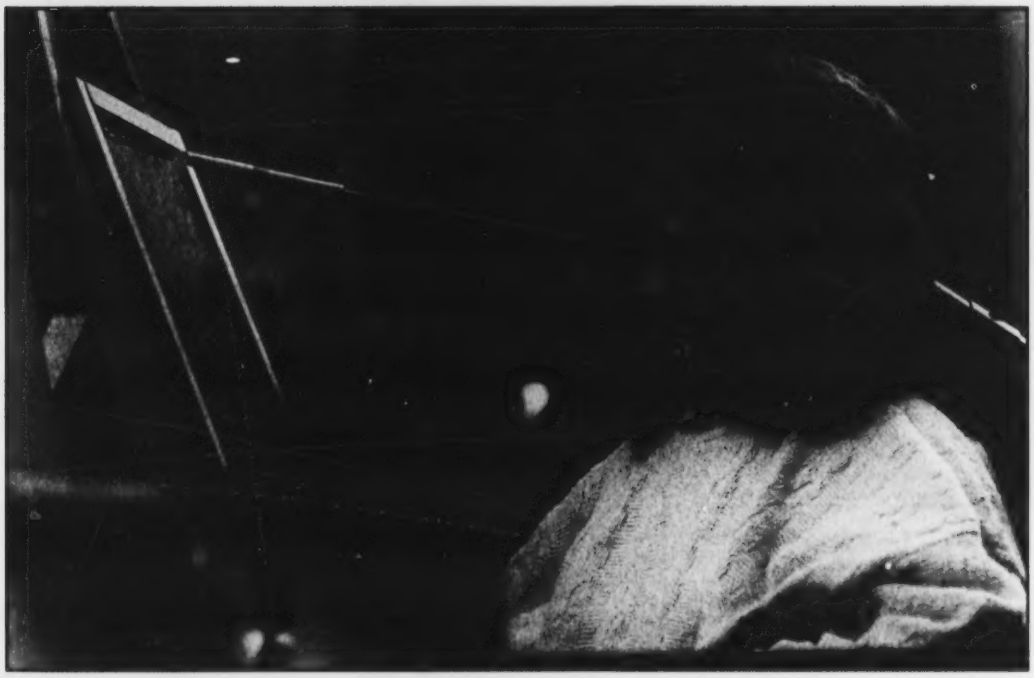

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Spring Time by Amy Neubauer

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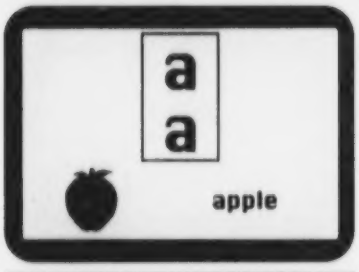

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metropolitan area, and our home was in the suburbs. Jamaica had many friends at school, but few opportunities for integration into the local community. It was still like she had a separate life from the rest of the family. Not every state has a residential school for the blind, and most schools are located in large cities. But we finally managed to locate a residential school in a small town—and we moved our family one last time.

Jamaica, now 17, lives at home and attends the school for the blind as a day student. Last year, she also spent part of each day integrated into a language arts class in the local high school, where she was with sighted friends she knew from church, gymnastics and Girl Scouts.

We believe Jamaica's well-balanced educational program is meeting her unique needs and preparing her for life in the real world. At the school for the blind, she gets daily instruction in orientation and mobility. She is learning to use new technology that enables her to communicate with people who do not read Braille. She is learning cooking and personal management skills to help her move toward a life of independence. Most of these opportunities would not be available to her in a public school program.

On the other hand, her progress in the integrated language arts class surprised everyone. By October, she had already met her goals for the entire year! There is nothing equal to the motivation offered by friends.

Today, 17 years later, I still believe in full integration—integration of all the supports and resources necessary to meet each child's individual needs. I become very worried when I hear talk of narrowing options and making services more generic. Instead, we need to broaden the educational opportunities available to children with disabilities and their families.

Has it been easy piecing together an appropriate educational program to meet Jamaica's changing needs? No! At different points along the way, we have used *every one* of the educational placement options available. Sometimes it seemed that our choices were very limited. But at least we *had* choices.

—Diane D. Miller
Vinton, Iowa

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I STILL BELIEVE IN FULL INTEGRATION—INTEGRATION OF ALL THE SUPPORTS AND RESOURCES NECESSARY TO MEET EACH CHILD'S INDIVIDUAL NEEDS.

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Circle #105

Agape Village

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Contact: Glenda B. Wallace, Ph.D., Agape Village
3711 Agape Village Rd., Macon, GA 31210, **912-471-3700**

Circle #261

"Real Inclusion" Starts With Us

It started simply enough as the 1991 school year began. Rather than busing our daughter, Sydney, who has Down syndrome, to the "special day class," we just opted to keep her in the local school. With that decision came a due process hearing, in which we prevailed, and a far more complicated process known as "inclusion." It is an ongoing journey, not unlike that faced by those who fought for racial desegregation, 40 years ago.

Inclusion is not easy or simple. It is fraught with all the many challenges we had been warned about. At least once a week, I resolve to throw in the towel and as gracefully as possible, slink off to the nearest self-contained class with Sydney in tow.

Sydney (right) enjoyed her fourth-grade field trip to the San Diego Zoo.

In the past, following every inspiring conference or seminar, I would return to our school district full of enthusiasm and great ideas. It always seemed that "real inclusion" was happening just about every place but here.

But I now understand that the reality of inclusion can be found in the process that is happening in my daughter's class. Inclusion, we have learned, is a state of mind. It is not easy to change the "non-person" category into which so many individuals with intellectual challenges are placed. What keeps us going is the absolute knowledge that our daughter, and others like her, deserve the right to become valid and valued members of the community. Meaningful inclusion must start here, and with us.

Still, it is hard not to get discouraged when Sydney plays alone at recess while her classmates giggle and laugh nearby. It sometimes takes my last bit of self control to field thoughtless comments—no matter how well intended—and the obvious lack of respect shown my daughter, unfortunately, all too often. It would be easier to escape from the assaults of the world, back into safer environments and settings. And who knows, perhaps someday we will.

But at discouraging moments, I try to reflect on Sydney's many accomplishments over these last three years. Now 12 and going into fifth grade, Sydney reads at her grade level, enjoys spelling and is mastering cursive writing. She takes piano and dance lessons, and has participated in her school's annual production of "The Nutcracker"—last year, as a candy flute.

Our goals for Sydney's inclusion are far more realistic now than they were at the beginning. Our family is facing the real world and trying to put together the many pieces that go into preparing any child for an independent and fruitful adult life. Inclusion doesn't mean insulation, and it doesn't mean automatic acceptance either. For that reason alone, perhaps inclusion isn't for everyone—but wouldn't it be nice if it were?

—Joyce A. Taylor
Lake Forest, California

WHAT KEEPS US GOING IS THE ABSOLUTE KNOWLEDGE THAT OUR DAUGHTER, AND OTHERS LIKE HER, DESERVE THE RIGHT TO BECOME VALID AND VALUED MEMBERS OF THE COMMUNITY. MEANINGFUL INCLUSION MUST START HERE, AND WITH US.

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Redefining "Least Restrictive Environment"

Allow me to describe the "least restrictive environment" for my son, the placement every parent dreams of. It's a school where my child will learn on grade level, in a classroom of same-age peers, with a minimum of extra support services. Free and easy communication will flow between my child, his peers and his teachers. Friendships will develop naturally—no one is receiving "extra-credit" to be my child's "buddy." He'll have the opportunity to earn a place on the honor roll without that damned asterisk after his name, to indicate "special educational programming." Of course, extracurricular activities will be wide open to my child! Join the basketball team? Sure, no need to include that on the IEP. Theater Club? No problem. Debate Team? Ditto. Student Council? Get out the felt-tip markers and start making campaign posters! Homecoming court, school dances, field trips, the prom—my child will have the opportunity to participate in any activity he chooses. No advance request necessary, no hurried meetings to adapt an IEP, no more frantic phone calls to the Statewide Family Advocacy Center for advice and support. My child will have the opportunity to join the clique of his choice and the opportunity to go out on a date. I can't wait to experience the "normal" headaches that come with parenting teenagers.

"Nice fantasy," you say.

"Dream on!" you smirk.

No, really! Every word is true! And every opportunity described above has become my child's daily reality.

But would you believe me if I told you I refused this very placement for years? That's true, too. The very "normal" educational experience I just described is available for my son only at the state school for the deaf, a residential school located almost 200 miles away.

For too many years, I put all my child's eggs in the "least restrictive environment basket"—in other words, our neighborhood school. As far as I was concerned, there was no option; he had to go to school here. Period. End of discussion. He had to learn to live in our "hearing world." We made academic plans that had to be modified and sometimes sacrificed. My son had limited friendships and no real social life.

Then I began to meet adults who were deaf. I began to listen to their conversations, their stories, their experiences of learning to live in the "hearing world." Slowly, oh so very s-l-o-w-l-y, something began to nag at me. A light bulb went on in my head and steadily burned, becoming brighter and brighter. Finally I realized this: as much as we love our son, as much as we are willing to advocate for every right to which he is entitled, my husband and I are still hearing people. We could never teach our son how to live in a "hearing world." He can learn that only from the very people who have done just that since the beginning of time—other people who are deaf.

So please, I am asking all of you who advocate for integration and inclusion, please tread lightly. What might be right for your child will not be right for mine. Don't overlook the law's guarantee of a "continuum of placement options." You, too, may need that guarantee someday.

As for me—I gotta run. I need to get to the store before it closes. I have to buy a new outfit for the homecoming game. It's Parent's Day at my son's school, and I wouldn't miss it for the world!

—Susan K. Perrault
Oneida, Wisconsin

ALL OF YOU WHO ADVOCATE FOR INTEGRATION AND INCLUSION, PLEASE TREAD LIGHTLY. DON'T OVERLOOK THE LAW'S GUARANTEE OF A "CONTINUUM OF PLACEMENT OPTIONS." YOU, TOO, MAY NEED THAT GUARANTEE SOMEDAY.

Jacob Gillis, 16, shows off his favorite Christmas gift—a varsity jacket! Jacob, a member of the class of 1997 at the Wisconsin School for the Deaf, has competed for the school in football, basketball and track. Jacob was the foster son of Susan and Richard Perrault for more than eight years.

A Report From the National School Bus Standards Conference

Ricon recommends ADA lift standards for specially-equipped school buses

Once every five years, school bus operators from across the country gather to update a document known as the "National Standards for School Bus Operations." The 12th National Conference on School Transportation Standards, held May 21–25 1995 in Warrensburg, Missouri, marked the occasion of the most recent update to this document—including significant upgrading of the standards for specially-equipped vehicles used to transport students with disabilities.

Prior to the conference, several key equipment manufacturers, who served as advisors to the Standards Committee, presented recommendations on upgrading standards for various types of school bus equipment. Ricon Corporation, a leading lift manufacturer, presented a draft recommendation to upgrade equipment standards for specially-equipped buses used to transport students with disabilities. The Ricon recommendations were supported by other lift manufacturers, and were eventually accepted for adoption by conference delegates.

Although school buses are not required to comply with provisions of the Americans With Disabilities Act (ADA), the 281 delegates to the conference approved the Ricon proposal, a document that borrowed heavily from the ADA to describe standards for specially-equipped school buses. The Specially-Equipped School Bus Writing Committee used language similar to that used in the ADA to outline rules on passenger capacity, lift and ramp specifications, window glazing, aisle width, markings, securement systems and new technology.

Committee co-chair David Huff, a delegate from Montana, said the conference adopted "90 percent" of the ADA's requirements, but rejected as unnecessary an ADA requirement for door height sufficient to accommodate adults in wheelchairs. Consistent with ADA standards, however, the conference added the requirement for school buses to have a parking brake interlock, a mechanism that prevents lift operation if a vehicle's parking break is not engaged. This requirement will ensure that a school bus cannot roll while its lift is in use.

According to Dale Carpenter, vice president of sales for Ricon Corporation, "The difference between a lift that doesn't meet ADA requirements and one that does is about $95." Carpenter added that the cost may go down as such modifications become standard within the industry.

Electronic communications systems

Illinois delegate Peter Grandolfo and delegates from other urban states argued for requiring an "electronic voice communications system"—meaning either a radio or a cellular phone—on each bus that transports students with disabilities. But delegates from mountainous and rural areas disagreed with that proposal. Utah delegate Ben Black, of the San Juan school district, was typical of the dissenters. "It's pretty obvious to me that a lot of these folks have never been out West," said Black. "I have 8,000 square miles of district to cover." Black went on to explain that his district includes places where neither radio nor cellular communications can be used.

Eventually, an amended version of the measure was passed. The new version excluded areas where electronic communication does not exist. In addition, the wording was changed to say that electronic communication "should" be required, rather than "shall be."

Testing tie-downs

The conference deleted an earlier version of its own testing standards to allow the Society of Automotive Engineers (SAE) to do even more stringent testing of wheelchair tie-downs. SAE tests will involve wheelchair-and-restraint/securement systems being smashed on a test sled at 30 m.p.h. Huff said the decision to go to SAE testing will "put teeth" in the standards adopted by the convention, "to see if these tie-downs are going to do what we want them to do."

Lift capacities

Members also voted to strengthen lift capacities by adopting the Ricon-recommended "design-load" standard of 600 pounds. In addition, delegates added a requirement that "the lifting mechanism and platform shall be able to lift a minimum of 800 pounds." This requirement should ensure that each bus has a lift with the capacity to safely and effectively lift even the heaviest power wheelchairs and their passengers.

Belt cutters

Finally, the conference required that a durable seat belt cutter should be kept in any bus that has wheelchair/mobility aids or "other assistive or restraint devices that utilize belts." The availability of the belt cutter means that in an emergency, a passenger can be quickly freed of the restraint system and evacuated from the bus.

Standardization leads to better service

The standards passed by this convention will be adopted automatically in four states and used as a guideline in most others. For companies like Ricon Corporation, the adoption of ADA standards for school-bus wheelchair lifts means a more standardized product, because these same lifts are already in use by paratransit systems that provide transportation to adults with disabilities. Because the same lifts will now be used in school buses, Ricon Corporation will be able to provide faster delivery times and better after-sale product support.

Ricon goes one step further

In assessing the impact of the new standards on student safety, Carpenter pointed out that the recent adoption of the ADA requirement for an inboard roll stop is a significant safety enhancement. The inboard roll stop is a 10- to 15-inch barrier that prevents a wheelchair from falling into the space between the edge of the lift and the side of the vehicle.

In addition, the new requirement for a supplemental restraint system means that all passengers using a bus equipped with a Ricon lift will be protected by a "safety zone" that includes an electrically-interlocked outboard passenger restraint belt. This exclusive feature—standard on all Ricon transit lifts—consists of a belt running across the outer side of the lift, above the outboard roll stop. This helps to protect passengers in wheelchairs from rolling off the non-vehicle side of the lift platform and falling to the ground.

Portions of this article were adapted with permission from SCHOOL TRANSPORTATION NEWS.

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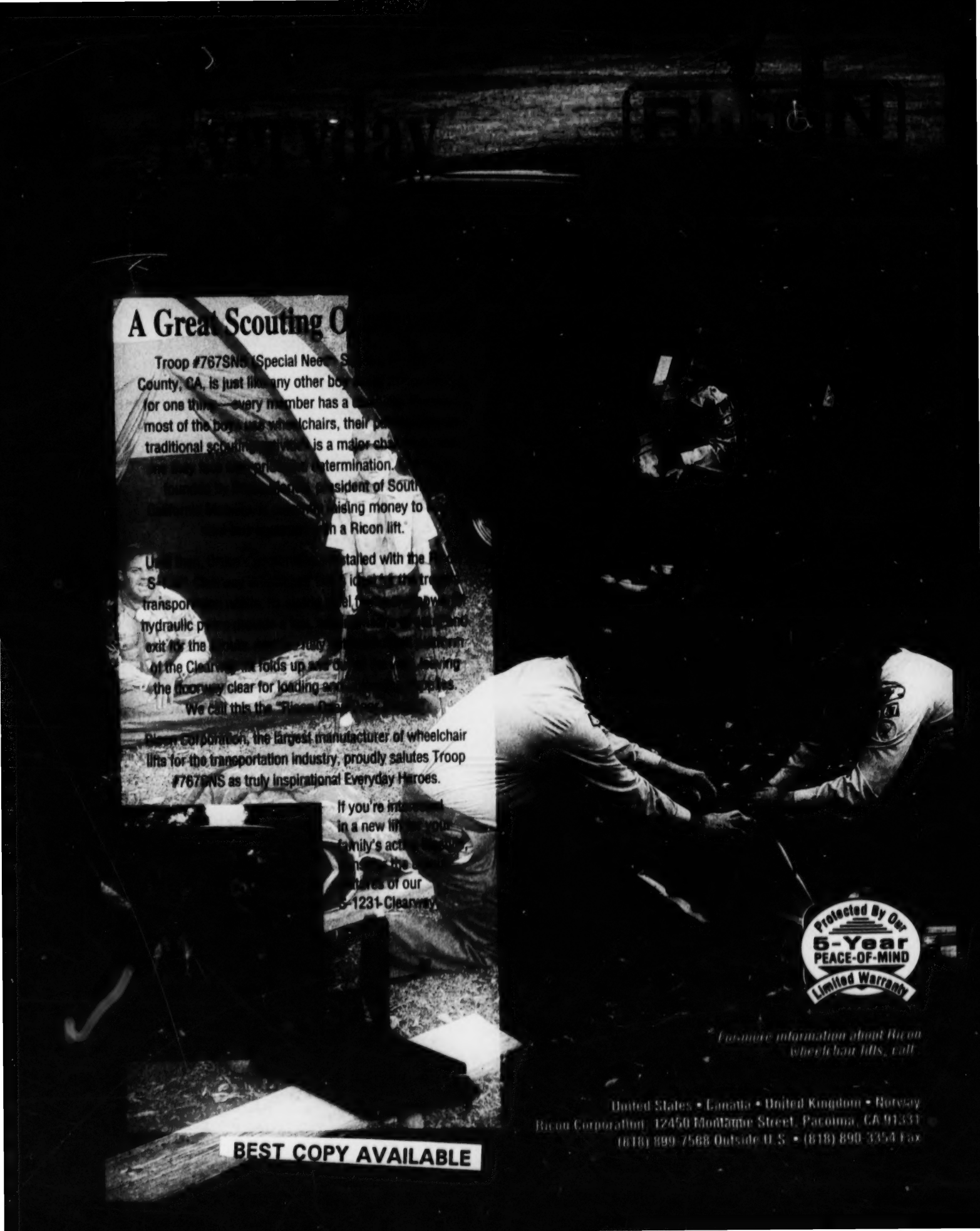
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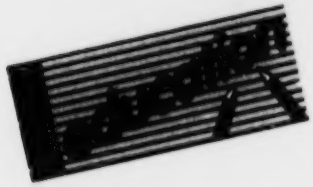

Guidelines for Using Transportation Services

by Ned Einstein

Few things in life run as smoothly as they should—parents are particularly reminded of this truth on most weekday mornings, as they rush to get children ready for school and out the door. Likewise, special education transportation services may not always run as smoothly as we might wish. But parents can do many things to help.

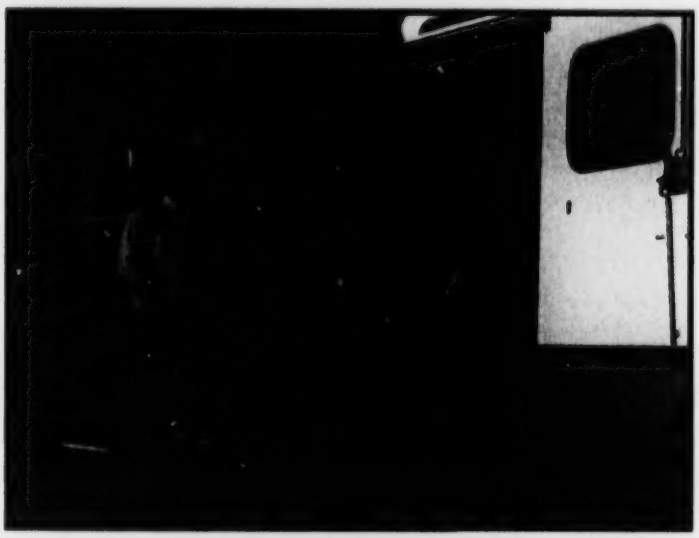

Photo courtesy of Ricon Corporation

Children and parents deserve safe, reliable transportation services that are responsive to their concerns. Parents pay for transportation services either directly, through fees; or indirectly, through taxes. They have a right to expect these services to operate according to some standards of quality. Unfortunately, laws and regulations establish only minimum standards; and some states have no legally mandated standards at all.

Regulations, standards and contract requirements may affect the safety, reliability and responsiveness of transportation services. In general, service quality depends largely on the money available to pay for it. Within these limits, however, most of a transportation system's operating characteristics are within the control of the personnel in charge of running it. But an informed parent can make many contributions to safety and service quality.

Understanding your transportation system

To passengers and their parents, the "system" may seem to be simply the vehicle and its driver. But your child's vehicle and driver are only one cog in a complicated system including layers of dispatchers, schedulers, telephone receptionists, mechanics, training instructors and managers. Vehicles must be purchased or leased, maintained, cleaned, fueled, inspected, licensed and insured, as well as scheduled and driven.

Under the best of circumstances, operating a fleet transporting hundreds of individuals with a variety of special needs, traveling in every direction at the same time, is a task of daunting complexity. Now imagine what happens when it rains… when new drivers are still learning their routes… when there are traffic delays and accidents… when passengers are not ready at their scheduled pick-up times… or when operating personnel are overwhelmed with telephone calls…

Parents can help

Parents can do much to help the transportation service run more smoothly. Here are a few guidelines:

• ***Be as flexible as possible in accommodating schedules.*** Scheduling hundreds of students for pick-ups and drop-offs is difficult. Adjusting a driver's schedule to accommodate a simple request—for example, "Can't you come earlier?"—can destroy the logic of an entire route, force other pick-ups to occur out of order and increase ride times for other children on the route.

• ***Provide system officials with telephone numbers where you or others responsible for your child may be contacted at all times.*** When a vehicle runs behind schedule, breaks down or experiences other problems, it can take hours to track down and notify each passenger's parents. Make sure operating personnel have the information needed to contact you quickly.

• ***Know your child's pick-up and drop-off times and the "window of flexibility" for each.*** For example, a 10-minute "window" for a pick-up scheduled to occur at 8:30 a.m. means the pick-up should occur between 8:20 and 8:40 a.m. Always try to have your child ready *before* the window of flexibility begins. When it rains or snows, have your child ready even earlier; a well-run system will automatically try to pick up its passengers earlier in bad weather. Do not telephone system personnel until the vehicle is genuinely late.

• ***Obtain telephone numbers of parents whose children are also on your child's routes.*** The most important numbers are those of passengers picked up and dropped off immediately

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before and after your child in the morning and the afternoon. Conversing periodically with fellow parents can help you monitor the quality of service and identify problems. If you are worried about a late vehicle, call a parent whose child is picked up (in the morning) or dropped off (in the afternoon) before yours. Better yet, appoint one parent to be "route captain;" that parent can communicate with system operator, then communicate individually with other parents of children on the route.

• ***Establish a clear policy with system officials about "receiving" your child.*** It may not be safe for the driver to drop your child off without a responsible adult available to meet him or her. Let system officials know who is authorized to meet your child.

• ***Make arrangements for your child to be dropped off at another home on the route if you cannot be home to meet the vehicle.*** Let system officials know who this will be. If no responsible adult is at the drop-off point when the vehicle arrives, the driver may be required to keep the child on the bus. Drivers usually do not have time in their schedules to "swing back" mid-route to drop off a child. In a case like this, your child could ride for hours until the driver has an opportunity to bring him or her home.

• ***Always call system personnel to cancel pick-ups and drop-offs if your child will not be riding.*** Make these arrangements as far in advance as possible. When you want transportation service resumed, also remember to call system personnel in advance.

• ***Provide system officials with detailed information, in writing, about your child's physical and medical condition(s).*** Include notes about behavioral issues, and any other special concerns. Also include phone numbers of your child's doctors. Ideally, the system should collect this information in the same way for all passengers. If it doesn't, at least make sure it has this information for your child.

• ***Do not alter regular pick-up or drop-off locations.*** Organized and productive transportation systems cannot juggle pick-up and drop-off points without inviting scheduling and dispatching chaos. If your child will be staying at someone else's home, make arrangements to have that person drive to the regular pick-up or drop-off point before the vehicle is scheduled to arrive, and wait for it there.

• ***Do not ask the driver to be a messenger.*** Call system officials to convey information, file complaints or ask questions. If a schedule change is necessary, don't discuss it with the driver; contact system officials directly. Don't ask the driver to transport notes, lunches or any non-health-related articles. Have your child do it.

• ***Communicate with system officials and personnel on all non-urgent matters during non-operating hours.*** Non-operating hours are those hours when children are in school. During operating hours, a system switchboard is often flooded with calls requiring immediate response from dispatchers and system managers. Unless there is an emergency or your child's vehicle is unusually late, do not contact system officials during operating hours.

Understanding the system from the "operating perspective"

Share these ideas with the parents of other children on your child's route and others whose children use the same transportation system. Your child's transportation system will operate more smoothly if other parents also follow these guidelines.

Try to remember that the people operating the system do not see it the way you do. They can't. *And they shouldn't.* This does not mean your child is "just a number." But system officials are often responsible for the safe, reliable transportation of hundreds of children. And they have to exercise this responsibility within a limited budget. While they try to accommodate most of their passengers' needs, they cannot possibly accommodate every need of every parent. When discussing problems with system officials, let them know you understand these realities. They will greatly appreciate your understanding, and in return you will receive better information about the system and help in solving problems. **EP**

Ned Einstein is the president of Transportation Alternatives, a southern California-based consulting firm specializing in the design of school transportation systems for children with special needs, and "paratransit" systems for adults with physical and developmental disabilities. A former consultant to the U.S. Department of Transportation, Mr. Einstein authored the summary report of the NATIONAL SURVEY OF THE TRANSPORTATION OF THE HANDICAPPED, a report to Congress that formed the basis of the transportation sections of the Americans with Disabilities Act (ADA). Mr. Einstein conducts workshops on special transportation services and regularly provides expert testimony and technical assistance to attorneys involved in transportation-related cases, particularly those involving paratransit, school bus and special education services.

What are your concerns about transportation services?

Do you think your child's ride is unreasonably long? Are you worried about safety issues? Do you wonder how your child's transportation provider chooses and screens drivers? Readers with transportation concerns may write to Ned Einstein, c/o EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. Mr. Einstein will answer reader questions in upcoming issues of the magazine.

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Your Child's Bathroom

Only after this sink has been adapted, can this young boy use it.

(Photos courtesy of the Center for Accessible Housing, Raleigh, NC)

When Jean and Mike Gibbons built their new house, they had to think carefully about their son Anthony's bathroom. Anthony Rubino, 13, has quadriplegic cerebral palsy, and Jean and Mike were determined to create a home in which Anthony could have as much independence as possible. One of the central features of that home turned out to be a ceiling-mounted lift that moves Anthony from his bed to the bathroom, and once there, from the toilet to the shower. The lift could be installed only because the Gibbons' architect made sure the configuration of the bathroom and bedroom was just right. Building a new home to meet the needs of a child with disabilities is clearly an ideal solution. Unfortunately, not everyone can start from scratch.

When designing a bathroom for a child with disabilities—either as an adaptation to your existing home or as part of a new one—there are several goals to keep in mind. Independence and privacy are primary among them; it is important that a child be able to do as much as possible without someone else's help. This means considering details such as the height of light switches and the placement of towel racks. These details, in turn, highlight another priority—safety. Towel racks need to be within reach, but should also be positioned where they will not be confused with grab bars (see sidebar).

Children grow older; this fact often influences design decisions also. In a few years, for instance, your child's grab bars may be positioned too low to be useful. Planning ahead can help you avoid these problems. Grab bars, for example, will be

Checklist for Your Child's Bathroom: Is it Convenient and Safe?

Remember that the bathroom must be big enough for your child and any adaptive equipment he or she needs, keeping in mind that both the child and the equipment will grow larger.

1. Personal Hygiene

- Is the sink at a good height for your child? Is it easy to adjust the height of the sink to accommodate your child as he or she grows?
- Is there a need for open space below the sink or vanity? If there is not a need now, will there be one in the future? If so, is it easy to remove cabinets to provide space?
- Can your child reach the faucet now? Do you anticipate further limitations in reach?
- Is the mirror at a good height for your child? Is it easy to adjust the height of the mirror? (Note: A large mirror meets the needs of everyone.)
- Is the toilet at a good height for your child? Is it easy to adjust the height of the toilet? (Note: Add-on seats are available.)
- Is the tub/shower easy to get into and use?
- Is there a tub/shower seat in the bathing area?
- Can the controls be reached from both a sitting and a standing position?
- Does the shower have a hand-held unit? Is it mounted so that your child can use it?
- Is the tub or shower floor a non-slip surface?

2. Support Systems

- Does your child need grab bars by the toilet? The height of the grab bars will need to change as your child grows; if the bars are mounted on solid blocking, is the blocking wide enough to allow the height of the bars to change substantially?
- Does your child need grab bars at the tub or shower? Is it easy to adjust their height? (See above.)
- If you have grab bars, are they sturdy? (Note: Towel racks are often used as grab bars, but they were not designed to fulfill the same purpose and should be placed where they will not be confused with grab bars.)
- Even if your child does not need grab bars, will the caretaker?

3. Accessories

- Is the toilet paper dispenser within reach?
- Are the towel racks at a good height for your child? Is it easy to adjust the height of the racks?
- Are the light switches easy to turn on and off?
- Are the electrical outlets appropriately placed? Do you need outlet covers?
- Are the electrical outlets grounded?

4. Storage

- Is there adequate storage within reach? Storage needs may change; is extra space available if needed?
- Are the medicine cabinet and shelves within reach? Are they easy to open?
- Is there enough room for toileting/diapering supplies? Is there a surface for diapering?
- Is there enough room around the sink for the accessories your child will eventually need, for example, shaving items and make-up?
- Is there space to store a shower chair that can be used in a roll-in shower?

5. Moving Around

- Is there space to move around in the bathroom in a wheelchair? Will there be sufficient space as your child and the wheelchair become larger?
- Is there room for both your child and a caretaker?
- Is the bathroom door wide enough? (Note: By widening it to 32" clear, it will meet your child's changing needs.)
- Is it easy to pull the door shut? Is it easy to open?

6. Lighting & Ventilation

- Is there enough lighting in the bathroom?
- Is the bathroom well-ventilated?

Adapted from material in A Consumer's Guide to Home Adaptation. $12; available from Adaptive Environments Center, 347 Congress St., Ste. 301, Boston, MA 02210; (617) 695-1225.

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Accessible bathrooms need not look institutional!

(Photo courtesy of American Standard, Piscataway, NJ)

easier to raise if you place wide, solid blocking behind the walls so the bars can be re-mounted at any height.

Development may also bring changes in a child's abilities. If your child may use a wheelchair in the future, for example, any under-sink cabinets need to be easily removable.

Resources

To begin gathering the necessary information to embark on an adaptation or design project, first get your child's occupational or physical therapist involved; that person can help you review needs and locate resources. Parents can search databases such as the ABLEDATA database of assistive technology (8455 Colesville Rd., Ste. 935, Silver Spring, MD, 20910-3319; 800/227-0216, V/TTY; 301/588-9284, V/TTY; BBS: 301/589-3563, 8-N-1, 1200–9600 baud). Other good places to find new products or services include:

• *Adaptive medical equipment retail dealer catalogs.* Medical equipment dealers can show you their catalogs to give you design ideas and options.

• *State assistive technology programs.* To find these programs, which can direct you to resources in your state, contact the RESNA Technical Assistance Project, 1700 North Moore St., Ste. 1540, Arlington, VA 22209-1903, (703) 524-6686, voice; (703) 524-6630, TTY.

• *Independent living centers.* These community-based, consumer-controlled advocacy and service organizations can provide lists of resources for adaptation projects. To find the center nearest you, contact the National Council for Independent Living, 2111 Wilson Blvd., Ste. 405, Arlington, VA 22201, (703) 525-3406, V/TTY.

• *Specialized accessibility consultants.* Make sure that any consultant you hire focuses on *residential* adaptations. These consultants, where available, help families target their specific design or adaptation needs. This process involves the whole family—it's important that a modification or adaptation for one family member doesn't interfere with the needs of another. After a discussion about needs, goals and options, the next step is research into resources and products. The consultant may serve as a liaison between the family, the contractor and the architect, to make sure all the necessary details are included.

Often, the ability to take advantage of design ideas, products and services relies on funding. Inexpensive solutions exist, but adaptation expenses inevitably add up. Finding funding requires legwork, and families have to be ready to live by the "bit here, bit there" principle. In order to finance the bed-to-toilet-to-shower lift, Anthony Rubino's family looked everywhere for help with the $10,000 bill. Eventually, the Knights of Columbus came through for them with a $5,000 contribution and the Elks with $100. As you investigate resources, be sure to ask for funding tips.

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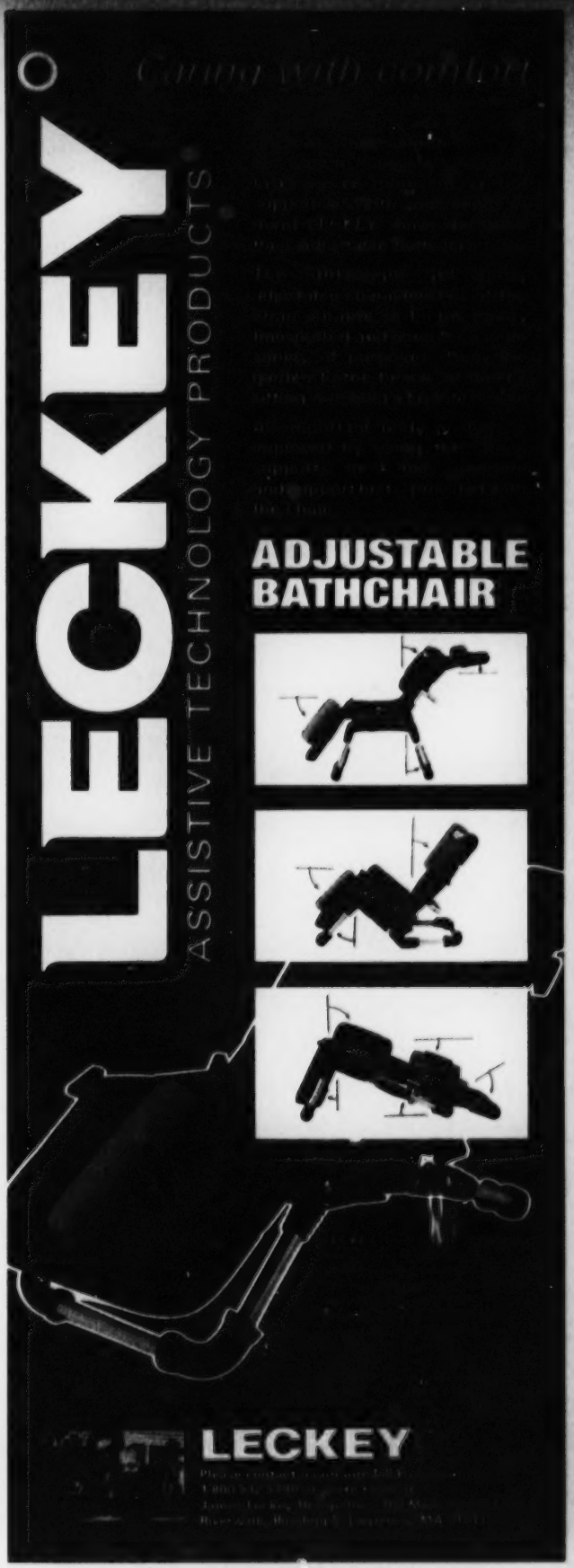

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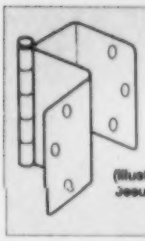

This Duro-Matic door hinge adds two inches of clearance to any doorway.

(Illustration courtesy of Duro-Med, Jessup, GA)

A balancing act

In designing or adapting a bathroom, each decision is a link in a chain of decisions; one change can demand a whole series of changes. If you are building a new home, you have a great deal of flexibility—as much as finances allow, you can aim for ideal solutions.

Modifying an already-existing house presents a different challenge; it forces you to find a balance between the ideal solution and the options dictated by circumstances. If you do not have room to replace an existing door with one that is three feet wide, you have to find another solution. If the child's wheelchair does not need to make a *turn* to enter the bathroom, the door can be narrower. Even if a turn is necessary, it may be possible to create the needed width with a pair of offset hinges. These hinges have an extra fold, allowing the door to open further back and to the side so the inside edge of the door no longer diminishes the doorway's full clearance. This $30 option may save a family up to $600 in reconstruction costs.

The bathing area demands similar considerations. If your bathroom already has a tub, you can install a lift—the most common type clamps onto the side of the tub. Or you could replace the tub with a shower, which may be easier to use. A pre-fab roll-in shower fits into the space of an existing tub. If the shower is not big enough for the caretaker as well as the child, a half-height curtain can allow the caretaker to work from outside the stall.

Circle #186

Blueprints

Talking about her work, accessibility consultant Jackie Dobson describes a moment she arrives at with many families—the moment when she says, "when your child moves to his or her own apartment..." Often, she can see that families haven't yet considered this eventuality—she watches them make a mental shift from the here-and-now to the future, and she can see their surprise. Jeff Jones, father of Brianne, a 14-year-old with cerebral palsy, is thankful for moments like that. "Jackie personalizes it. You're busy thinking about 2x4s and she reminds you that girls need space to be girls—space for the hair dryers, you know?" Sometimes, a blueprint for a bathroom can turn out to be a blueprint for independence. **EP**

—Molly Winans

Molly Winans is assistant editor of EXCEPTIONAL PARENT.

Thanks to the following people for their contributions to this article:

- *Jackie Dobson, president and founder of Solutions for Accessibility, Framingham, Massachusetts;*
- *Jean Gibbons, parent, Manomet, Massachusetts;*
- *Jeff Jones, parent, Cambridge, Massachusetts;*
- *Ralph LeBlanc, architect, Hull, Massachusetts.*

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Circle # 175

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The New England Center for Autism, is a community-based education center providing day and residential programs for students aged 3 to adult. Classes in communication, daily living, academics, employment and social skills are taught in 1:1 and low staff-to-student ratios. Our non-aversive approach is designed to bring children out of the severe isolation imposed by their disabilities and prepare them for productive, working lives in their own communities. The central educational facility of **The Center** is located just 20 minutes west of Boston, in Southboro, Massachusetts, with 13 attractive student homes in nearby communities. We are less than 3 hours from most eastern states and accept appropriate students from anywhere in the US.

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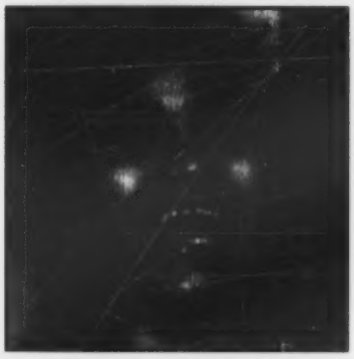

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We Can Make A Difference!

Circle #76

Genetic Counseling

Advances in testing are changing the "typical pregnancy"

PART TWO

by Naomi Angoff Chedd

"CVS... AFP... DNA analysis... I thought I was going to have a typical pregnancy. Instead I was thrown into cauldron of alphabet soup!" This was the reaction of one mother upon learning that her genetic history predisposed her unborn child to a number of genetic conditions, including a major heart defect. Her pregnancy—which involved close monitoring, numerous tests and then, neonatal heart surgery—was anything but typical.

These days, most pregnancies involve discussions of genetics, and many couples consult geneticists or genetic counselors. Some undergo a variety of tests in an effort to ensure that their developing baby is healthy, which, in most cases, it is. If not, prenatal testing can give families information and options.

But the accuracy of that information is crucial, stresses Suzanne Morse-Fortier, coordinator of the Down syndrome program at Harvard Community Health Plan and former board member of the Massachusetts Down Syndrome Congress. Morse-Fortier, who works with parents of children who have Down syndrome, or those who have received a prenatal diagnosis, believes that such parents receive too much negative and incomplete information because many medical professionals do not have up-to-date knowledge of various disabilities. For example, she points out, "People are often told that 30 to 40 percent of children with Down syndrome will have a heart defect, which is accurate. But they are not told that now, most of these heart problems are correctable."

Morse-Fortier thinks that couples with a prenatal diagnosis should find out as much as they can about the condition and available support groups and resources. They may also want to talk with other parents of children with a similar diagnosis.

On the other hand, Morse-Fortier adds, parents who have not yet decided whether to continue a pregnancy should not try to predict their child's future based on the way other children have turned out. "Do we parade expectant parents of what we believe will be typically-developing kids around youth detention centers, prisons—or Harvard University, for that matter—and tell them, 'Now pay close attention to this and think seriously about whether or not to continue your pregnancy, because your kid might end up here some day?' Of course we don't. Nobody can predict *any* child's future."

Available tests

About three or four in every 100 births results in some kind of genetic abnormality or "birth defect." Although tests are available only for a few hundred out of the thousands of possible conditions, medical knowledge and medical know-how are improving all the time. Here are some tests that couples planning or expecting a baby may encounter:

Prenatal tests:

• *Ultrasonography* (ultrasound) is a non-invasive procedure that provides a visual image of the fetus. An ultrasound can be used to determine the size of the fetus and approximate due date. A more sophisticated level-II ultrasound can identify some developmental and structural abnormalities, such as spina bifida, congenital heart disease and hydrocephalus. Results are usually available immediately, although further tests may be recommended to confirm a diagnosis.

• *Maternal serum alpha-fetoprotein (AFP) analysis*, a maternal blood test performed between weeks 16 and 18 of a pregnancy, indicates the level of AFP, a substance produced by the fetus and passed to the mother's blood. High

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No cure... yet

Samantha Metcalf, 22 months, tries out the slide at a local playground with some help from her mom, Emily.

Two-year-old Samantha Metcalf was born prematurely and diagnosed with cerebral palsy around her first birthday. Then, a few months later, Samantha's pediatrician noticed she had some "café au lait spots" (light, coffee-colored marks on the skin). Samantha was seen by a geneticist and at 18 months, diagnosed with neurofibromatosis (NF), a disease that causes tumors to grow along various nerves and sometimes in the bones and under the skin. The severity of NF varies widely—from almost unnoticeable to quite disfiguring. It can also lead to a number of medical complications including curvature of the spine, enlarged head, blindness and neurological problems.

"We got lots of information from our geneticist," explains Samantha's mother, Emily. "At first the picture sounded bleak. But we found out that there's a range of possibilities. The disease may amount to a few large spots on the skin—which is most likely—or it may become more serious."

Samantha's NF is not related to her cerebral palsy or prematurity. It was caused either by a new mutation or by an altered gene inherited from one of her parents. NF is inherited as a dominant condition, meaning only one gene needs to be altered in order to have the disease. So if one parent has NF, each pregnancy has a 50 percent chance of producing a child with the disease.

DNA testing is now possible in most families with NF. The Metcalfs, who are awaiting the results of their DNA test, say, "We would go through prenatal testing if we decided to have a second child, although the test can't tell how severe the disease will be." Emily, who suspects she, too, may have a mild form of the disease, adds, "I'm optimistic about the future. When Samantha was diagnosed nine months ago, there was no prenatal test for NF. Now there is. Science is moving so fast, it gives us hope that they'll find a cure or a way to control the disease."

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New technology an option for some

During her first pregnancy, Renee Abshire, then 20, and her husband David, 24, never gave genetics a passing thought. But when their daughter, Maigon, stopped crawling and holding her bottle at seven months of age, they began to worry. Their pediatrician told them Maigon was "just getting a little lazy."

But as Maigon's condition worsened, Renee and David became increasingly concerned. The day Maigon had 39 seizures, the Abshires rushed her off to one of Louisiana's top medical centers, where doctors took a detailed genetic history and ran dozens of tests.

Since the Abshires are of Cajun decent—Louisianians descended from French-speaking immigrants from Acadia, a region of eastern Canada—none of the specialists they consulted ever mentioned Tay-Sachs disease, which had always been thought to occur almost exclusively in Jews of eastern- and middle-European ancestry. But when a neurologist thought he saw the characteristic red spot in the center of Maigon's eye, he ran the test for Tay-Sachs and confirmed the fatal diagnosis.

Renee was alone when a doctor told her, "Maigon has about three months to live." Today, many years later, she still feels that, "even with all the years of studying and experience doctors have, they just don't know how to deliver bad news. They should take courses on this. It's as important as anything else they do."

After Maigon died at age three and a half, the Abshires didn't even think about having more children. "Nobody can put a child or themselves through this a second time," says Renee, who started the Louisiana Chapter of the National Tay-Sachs and Allied Diseases Association. The Abshires knew they had a one-in-four chance of having another child with Tay-Sachs, and although prenatal testing was available, Renee and David knew they would never terminate a pregnancy.

(Above) Proud father David Abshire holds newborn daughter Brittany Nicole for the first time. (Right) The new family sits for a portrait: Renee holds one-week-old Brittany, while David holds a picture of the couple's first daughter, Maigon Nicole. Maigon, who is 32 months old in the photograph, died six months after it was taken. "This is our only complete family picture," says Renee.

But five years later, they learned about a new reproductive technology—"pre-implantation diagnosis." In this modified version of in-vitro fertilization, the mother's egg is fertilized by the father's sperm in a petri dish in a laboratory and allowed to grow to the eight-cell stage. Then a single cell is removed from the embryo and can be tested for a variety of diseases, including Tay-Sachs. If the embryo is disease-free, it is placed in the mother's uterus, with about a 20 percent chance of subsequent pregnancy and live birth.

Despite these low odds, the Abshires opted to try the new technique. Renee adds, "Even though the embryo might test negative for Tay-Sachs, we knew our baby could have another disorder. But we were willing to accept and love the child, no matter what."

Eight months after implantation, Renee gave birth to a daughter, Brittany, and the Abshires became the parents of the first-ever baby born with the help of pre-implantation diagnosis for Tay-Sachs disease.

Now 18 months old, Brittany Abshire did need surgery after birth to treat a hip dislocation. "But," says Renee, "She's absolutely perfect to us. And each day she reminds us to rejoice and live every moment to the fullest."

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levels may indicate twins or that the due date has been miscalculated and the pregnancy is further along. But it may also indicate, among other things, that spina bifida is present or that the fetus has died. Because the maternal serum AFP analysis is only a screening test, amniocentesis and/or ultrasound are generally performed to clarify the cause of elevated AFP levels.

Low AFP levels may also warrant follow-up. Recently, doctors have discovered that women who have given birth to children with Down syndrome have very low AFP levels. So some clinics recommend amniocentesis and chromosome analysis if the AFP level is unusually low. At many clinics, testing for the levels of two hormones, estriol and human chorionic gonadotropin (HCG), has been added to the AFP analysis. Low AFP levels, combined with high HCG and low estriol levels, indicate a higher risk of Down syndrome.

• *Amniocentesis*, a widely-used procedure usually done between weeks 15 and 18 of a pregnancy, provides clear results 99 percent of the time. In this procedure, normally done on an outpatient basis, a small amount of amniotic fluid is obtained by passing a needle through the abdomen into the uterus. The cells in this fluid are analyzed for chromosomal disorders, and the fluid is analyzed for AFP levels. Additionally, if the family has a history of a particular genetic disorder, amniotic samples can be tested biochemically or by DNA analysis.

Amniocentesis carries a slight risk of infection as well as a small increase in miscarriage rates. Many women report some pain connected to the procedure. Women older than 34, or couples who have already given birth to a child with a chromosomal or genetic disorder or have a family history of such a disorder, are generally offered this procedure. Results are available in two to three weeks.

• *Chorionic villus sampling* (CVS), done during the first trimester of pregnancy, allows doctors to diagnose many of the same conditions as amniocentesis, but earlier in the pregnancy. In this procedure, done on an outpatient basis, a sample of the placenta is obtained by passing a plastic tube through the vagina and into the uterus, or by passing a needle through the abdomen and into the uterus. CVS carries a higher risk of miscarriage than amniocentesis; also, some reports have suggested it is responsible for a rare limb defect.

Newborn screening:

Some type of newborn screening is mandated in most states. In most, babies are tested for metabolic disorders such as phenylketonuria (PKU), maple syrup urine disease,

Continued on page 78

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Nestled in the serene beauty of western Massachusetts' Berkshire Hills, Berkshire Meadows' carefully designed fifteen-acre campus offers a comprehensive, integrated year-round residential program for children and adolescents who are severely developmentally delayed and may be multiply disabled.

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The young people live in spacious one-story homes, each with its own lounge, visiting area , kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

Each resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

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Our intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

Berkshire Meadows
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Circle # 10

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homocystinuria and galactosemia. Some states also test for sickle cell disease, toxoplasmosis and endocrine disorders such as hypothyroidism and congenital adrenal hypoplasia. Screening for these disorders involves blood and/or urine analyses that can be done during the first few days of life. If a disorder is detected, treatment can be started immediately, and in some cases, physical or cognitive disabilities may be prevented.

Newborns can also be screened for hearing impairment using the brainstem auditory evoked response (BAER) test, which measures the brain's response to sound. Such testing is now mandated in several states.

If a problem is suspected:

Other tests that can be performed on newborns or older infants and children are not done routinely; rather, they are performed only if the child is suspected to have a specific condition. For example, children suspected of having a chromosomal abnormality such as Down syndrome, Turner syndrome, Klinefelter syndrome or others, can be diagnosed through chromosome analysis. This analysis can be done with a blood sample from the infant, which requires three to four days of cell growth in the lab, or with skin or other tissue samples, which require several weeks of cell growth. The analysis is done by examining stained cells under a microscope to look for extra, deleted, inverted or translocated chromosomes.

Screening for rarer types of metabolic disorders—such as the mucopolysaccharidoses or Tay-Sachs disease—is not done routinely at birth, but can be performed any time a problem is suspected. Testing for these enzyme deficiencies involves the

Dealing with a lethal diagnosis

After many years of infertility, Andrea and Peter Hart* became the proud and happy parents of a six-month-old adopted son. Then, unexpectedly, 39-year-old Andrea became pregnant. Her pregnancy progressed normally until week 20, when she went for what she thought would be a routine ultrasound.

But nothing turned out to be routine. Andrea and Peter's child was diagnosed with thanatophoric dysplasia, a growth disorder occurring once in about 10,000 pregnancies. The Harts consulted a genetic counselor to learn about the rare condition. Andrea explains, "We knew we could live with all kinds of disabilities, but these are the words that stuck in our minds: 'Your baby's condition is uniformly lethal.' So we made one of the most difficult decisions of our lives—to terminate the pregnancy." Throughout the emotionally and physically painful process, their genetic counselor was by their side, providing support and reassurance and helping them through their grief.

Afterwards, Andrea and Peter found a support group for people who have terminated a pregnancy after a prenatal diagnosis. "This is not the kind of thing people talk about openly or casually," says Andrea. "So you may never meet anybody else who has gone through a similar experience unless you join a group like this. It really helps to talk and listen to others."

** Names have been changed.*

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Circle #213

analysis of blood and/or urine samples.

An infant suspected of having cystic fibrosis may be given a sweat test, which measures the level of sodium chloride in a child's perspiration. A high level most often indicates that the disease is present.

Many other tests are available for diagnosing neurological disorders. These include various types of brain "scans" such as the electroencephalogram (EEG), which records the brain's electrical impulses; computerized axial tomography (CAT or CT scans) and magnetic resonance imaging (MRI), both of which can provide cross-sectional images of the brain's structures; and positron emission tomography (PET scans), which can be used to study the metabolic and chemical activity of the brain.

Most medical professionals would agree that the "typical pregnancy" is fast becoming a thing of the past. As a result, families are often faced with decisions for which they are unprepared. As more and more families face the difficult decisions created by progressively more sophisticated medical testing, the role of the genetic counselor may become increasingly important. One counselor put it this way: "If I can provide a greater level of comfort to people who need it, help them become better able to cope and give them enough accurate information to make decisions about their children or future children, then I am doing my job." **EP**

Naomi Angoff Chedd is a member of EXCEPTIONAL PARENT'S *editorial staff.*

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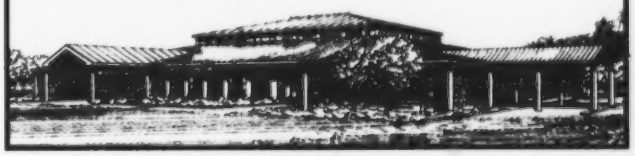

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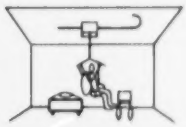

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Irene Pollin, author of TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS, *is a parent and psychiatric social worker. In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope with long-term effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed. After the loss of two of her own children, Pollin returned to school for training as a psychiatric social worker.*

Although TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS *was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members.* TAKING CHARGE *is available from Except-ional Parent Library (800/535-1910). The following is an excerpt:*

Mastering Your Fear of Expressing Anger

Anger is often difficult to recognize and acknowledge in oneself. You pay dearly when you cover your anger, trying to appear cool and controlled when you're not.

I know this from personal experience. I had no idea how much anger had affected my life—I didn't even know that I was angry. Some of my friends recognized it in me, but when one of my confidants mentioned that she thought I must be pretty enraged at what had happened to my family, I reacted as if she were crazy. "How dare she think I'm angry," I thought. "I'm upset and unhappy because of my children's deaths, but angry? Never."

Of course, I sometimes felt that

my life was over—I had put so much of it into my futile attempts at saving my sick youngsters. And certainly, I had asked myself repeatedly why two innocent children had to be born with such serious illnesses and had to suffer so. I wondered why all of my friends seemed to be able to give birth to one healthy baby after another, while two of my three biological children were so terribly sick. I questioned if there was anything I had done to cause my children's pain, for I was certain that they had no responsibility in it. These concerns plagued me for years, yet I never recognized that I was angry…

> WITHOUT WORKING THROUGH MY ANGER, I COULD NEVER RESOLVE MY GRIEF. ONCE I FACED THESE FEELINGS, I COULD REGAIN CONTROL OF MY LIFE.

Indeed, I realized that sometimes I was impatient and short with my family… In addition, I felt deeply disappointed in close family and friends who seemed to misunderstand me. I used to ask myself, "Don't they know how terrible I feel? Can't they read me?" On many occasions, I sat in one room feeling as if my world had fallen apart, while my husband and surviving children laughed at a TV sitcom or cheered a sporting event in an adjoining room. If, in my state of upset, I came out to talk to them about my feelings, they gave me strange looks rather than sympathy or support. I needed their love and understanding, but felt, instead, isolated, insecure and "crazy…"

My family… must have felt that I had changed. I knew I hadn't. Inside, I was still the same person, but I was hurting so much that I had no way to express it.

Moreover, my attempts at hiding my rage and pain made outsiders believe that I was cold and detached… In truth, I appeared calm because I was on tranquilizers… My doctor's idea, of course, was to get me through this difficult period, but in fact (as I realized later) the medication delayed my undergoing a process that was vital to my recovery.

Without working through my anger, I could never resolve my grief. Once I faced these feelings, I could regain control of my life…

Use words to express your feelings

Anger can be understood, tolerated and discussed. For example, begin by explaining why it's so important for you to express your anger. Ask for indulgence and help. Tell your family that it feels awkward for you to be angry, but you know that you must be. You can even explain that you're not exactly sure why you feel this way, but you'd like their forbearance as you go through this difficult process.

You can also explain to your loved ones that all you want is an ear. You don't need them to solve your problems—they may be unable to, anyway. But their listening will give you a chance to release some of your pent-up feelings. It's something positive they can do for you.

In your discussion, simple expressions like "I feel so frustrated!" or "Sometimes I feel sorry for myself!" or "I'm just enraged!" help to break the ice without explosive outbursts that can be dangerous to you. You are describing how you feel without blaming anyone. And your loved ones will respond, but without an argument. They won't feel attacked or

817

need to defend themselves. After you have expressed your anger, its intensity will have diminished and you will regain a sense of control.

ANGER DUMPED INDISCRIMINATELY MAY BRING TEMPORARY RELIEF BUT CAN PERMANENTLY DAMAGE RELATIONSHIPS YOU REALLY CARE ABOUT.

Be careful when you speak that you don't say things that can never be retracted or forgiven... Use "I" statements about your feelings (such as "I feel hurt when you don't call.") rather than "you" statements (such as "How dare you not call!"). Your friends and family will experience the latter as a form of verbal aggression and will become defensive. Anger dumped indiscriminately may bring temporary relief but can permanently damage relationships you really care about. "I" statements will garner a more positive response...

Finally, observe if your words and actions are in sync with your feelings. If you watch yourself, you may discover that you are one of those individuals (like me) who hide their true feelings. I learned that people often misread me because I continued to smile, even when I spoke of painful subjects. How could others know that I was hurting when my demeanor gave them a different message? While you may think that you are expressing how you feel, you may be conveying mixed messages. Make sure that those with whom you communicate fully understand you. **EP**

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You can see the delight in Rebecca's eyes. When she answers a math question in her fifth-grade classroom...or creates art to hang in the halls of her school...or sings with the choir in a program at City Hall...she enjoys discovering her world.

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Most all work in special education is focused on the child, his development status, his needs, his psychology, and the methodology required to educate him and develop in him the skills of independent living to the greatest degree possible. While the emphasis on the child is certainly required, in all the effort expended, parents have received very little attention. What happens to parents when their child is born with a severe handicap? What is the effect upon the marriage? How do parents deal with the emotional, social, and financial problems presented? How do they find services? What happens when services are far away or not even available? How does a severe handicap change parents and their attitudes toward their own child, toward the medical profession, and toward governmental authorities? This book attempts to answer these questions through the voices of parents themselves to give the reader a better understanding of the coping process. Parents from differing backgrounds and cultures present their personal accounts of how they dealt with their handicapped child from birth through adulthood. After each story there is an interpretation and commentary by an authority in the field of special education. The distinctive nature of this book is not to draw particular conclusions but to give the reader a view into the lives of a group of parents who have had to deal with some of the most difficult problems a parent can face and how they found the inner resources to cope.

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☐ Thompson, Richard H. & Gene Stanford—**CHILD LIFE IN HOSPITALS: Theory and Practice.** '81, 286 pp., 1 table, $38.95, spiral (paper).

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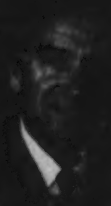

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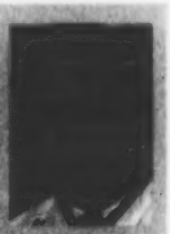
ASK THE DOCTOR

by David Hirsch, M.D.

"Burping" Through G-Button

Q My daughter had a Nissen fundoplication at the age of nine months and had a gastrostomy tube (g-tube) placed at the same time. The swallowing disorder that necessitated the g-tube (a button has since been placed) was felt to be caused by complications of a craniofacial condition. This condition was corrected by surgery and by her own growth. She is now five years old and is able to eat and drink well. We do not use the gastrostomy to feed her anymore and would like to have it removed.

Our problem is that the Nissen worked too well, and she is unable to burp. Our daughter's surgeon feels that the opening between her esophagus and stomach is normal for her age and doesn't think anything else can be done. But because she cannot release air through this passage, she often becomes uncomfortable during meals and asks us to vent the air in her stomach through her gastrostomy button. We are afraid to remove her button at this time because she needs it to burp, but we would like to remove it because she does not need it to eat. Will she need to keep it forever?



In this column, David Hirsch, M.D., a pediatrician and member of the EXCEPTIONAL PARENT'S *Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mentions of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, *209 Harvard Street, Suite 303, Brookline, MA 02146-5006, (617) 730-5742 (Fax).*

A Your daughter has a problem we typically do not see. In fact, many children with fundoplications (a surgical procedure where the opening between the lower end of the esophagus and the top part of the stomach is narrowed to prevent stomach contents from flowing backward into the esophagus), who are not yet oral feeders, often need to have the fundoplications re-done after five to seven years.

Your daughter may need intermittent dilatation of the valve between her esophagus and stomach—a procedure in which the sugeon enlarges that opening by stretching it—even though it appears to be "normal" in size. Also, medications to relax the sphincter (valve) between her esophagus and stomach may be helpful. Again, however, this is not commonly done.

Have you tried using some of the common "gas" medications such as simethicone? This medication may help to break down some of the large air bubbles in your daughters stomach into smaller ones that are easier to pass. Some of the newer medications that increase gastric and intestinal motility (the ability of the gastrointestinal tract to propel digested food through quickly) may also be useful.

As your daughter gets older and bigger she will probably "outgrow" this problem. But until you see some improvement in her condition—as a result of trying some of these suggestions or because of the passing of time—I believe you should leave the button in place, as long as no further complications occur. But ask your daughter's surgeon about the possibility of replacing the existing gastrostomy button with a smaller one. That will allow for quicker closure of the opening in her stomach when you are finally able to remove it. **EP**

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Circle #184

Issues and Answers

Books and Videos About Living With Seizures

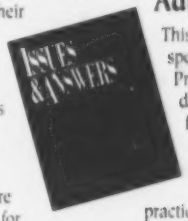
Issues and Answers: A Guide for Parents of Children with Seizures, Birth to Age Six

Comprehensive guide to help parents of very young children with epilepsy understand and manage their child's seizure disorder.

Answers common questions about epilepsy (seizure types, medical testing and treatment) and addresses family relationships, parenting skills and child development. Information about resources and questions about child care are discussed. (1993)

Catalog # 205GPB **$11.66 EFA Member**
105-Page Guide **$12.95 Non-Member**

Issues and Answers: A Guide for Parents of Children with Seizures, Ages Six to Twelve

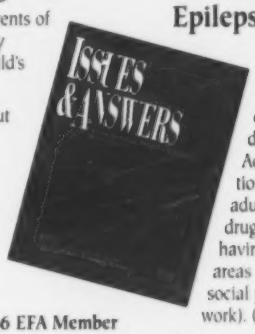


Comprehensive guide to help parents of children ages 6-12 understand and manage their child's seizure disorder.

Answers common questions about epilepsy (seizure types, medical testing and treatment) and addresses parenting skills and developmental stages of this age group. Discusses how to help your child succeed in school and addresses afterschool care concerns. Includes list of resources for parents. (1993)

Catalog # 206GPS **$11.66 EFA Member**
102-Page Guide **$12.95 Non-Member**

Issues and Answers: Exploring Your Possibilities: A Guide for Teens and Young Adults with Epilepsy



Comprehensive guide to help teens and young adults with epilepsy lead a full and healthy life. Answers common questions about epilepsy (seizure types, diagnosis, testing and treatment). Addresses common myths, misconceptions, and concerns of teens and young adults (medication side-effects, drinking, drugs, participation in sports, driving and having children). It also reviews many other areas of concern (school, behavior, friends, social pressure, independence, college and work). (1992)

Catalog # 165ITA **$11.66 EFA Member**
73-Page Guide **$12.95 Non-Member**

Issues and Answers: A Guide for Parents of Teens and Young Adults with Epilepsy

This guide will help parents understand the special concerns of their teen with epilepsy. Provides general information about seizure disorders (causes, testing, and medication), and focuses on helping young people with epilepsy develop a positive attitude. Information about social issues (dating, driving, drinking, drugs and marriage) are addressed and practical suggestions for helping young people with epilepsy adjust to and cope with the disorder are also included. (1992)

Catalog # 164IAP **$11.66 EFA Member**
110-Page Guide **$12.95 Non-Member**

The Teacher's Role, A Guide for School Personnel

Tips on recognizing seizures and handling a seizure in the classroom are reviewed. Additionally, provides guidance on how to help other children understand epilepsy and how epilepsy may affect school performance and behavior. (1986)

Catalog # 074TTR **68¢ EFA Member**
14-Page Pamphlet **75¢ Non-Member**

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HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

The Usual and Customary Rate

Q My son is a bright five-year-old with spastic quadriplegic cerebral palsy. He has had a manual wheelchair since he was two.

It is very tiring for my son to move himself from one location to another, so usually we push him. I have been considering a power wheelchair to give him more independence.

He's now covered under a comprehensive major medical plan. I know they provide coverage for durable medical equipment, and I know what to do to convince the insurance company of the medical necessity of a power wheelchair.

My concern is the insurance company's use of the phrase "usual and customary amount." A power wheelchair is expensive, and the amount the insurance policy will pay may be much lower than its actual cost.

What recourse do I have if my insurance company determines that our claim is greater than the "usual and customary amount?" How would I handle a scenario in which I find an appropriate wheelchair for $23,000, and the insurance company determines that $12,000 is the "usual and customary amount?"

A Disagreements between consumers and insurance companies often center around the issue of "usual and customary amount"—or "usual and customary rate" (UCR), as it's technically called. The insurance company calculates the UCR by analyzing the charges for a medical procedure or piece of equipment from a number of medical providers in the same geographic area.

It's important to remember that insurance policies sometimes set payments to a specific "percentile" of the UCR, rather than to the full UCR. Percentile is a complicated statistical concept. In this case, a percentile generally refers to the level at which a specific percentage of charges fall. For instance, if a charge falls at the 80th percentile, 20 percent of medical professionals charge more than that amount, and 80 percent charge less.

Let's say that a consumer has filed a claim for $150 for a medical procedure. If the UCR is $130, and the policy provides for payment at the 100th percentile of the UCR, $130 is the maximum amount the insurance company will consider paying, even though the original claim was for $150. However, if the policy provides for payment at a lower percentile of the UCR—the 80th percentile, for instance—and if the 80th percentile of the UCR is $115 for that procedure, then $115 becomes the maximum amount the company will consider.

Given the practice of setting payments to specific percentiles of the UCR and given the high cost of power wheelchairs, your concerns are valid. Fortunately, there are several steps you can take to avoid a situation in which you purchase a power wheelchair and then find the insurance company will reimburse you only for a small percentage of the bill.

First, work with your child's doctor and physical therapist to determine the specific power wheelchair and accessories your son requires. Then ask both doctor and therapist to write letters to the insurance company listing those items in detail.

Second, before you purchase the wheelchair, ask the doctor to file a "pre-determination of benefits" request with the insurance company. (A copy of the letters from the doctor and physical therapist should be included with that request.) Insurance companies generally respond to a request for a pre-determination of benefits within a few weeks. That response usually includes a summary of the claim and an estimate of the amount the insurance company will consider paying when the claim is approved. You can then decide whether to purchase the wheelchair or—if the insurance company's estimate appears too low—whether to file an appeal.

Some insurance companies have specific requirements for the purchase of expensive medical equipment. If you decide to purchase the wheelchair, make sure you follow those requirements in detail. **EP**

The Arc Plan and the COBRA Law

Recently, I've received a number of letters from readers asking about the availability of health insurance for children with disabilities. Several letters ask specifically for information about The Arc's new major medical plan; others just request information about any health insurance plan that might consider insuring a child with a disability.

In some cases, The Arc's new health insurance plan may provide a solution. The Arc plan, however, is only available to Arc members and members of their families, ages 10 to 65. In addition, while the plan does not automatically exclude children with disabilities, there is no guarantee of acceptance; each applicant's medical history and insurability is evaluated individually. For information about The Arc Group Major Medical Insurance Plan, contact the Albert H. Wohlers Company, 1440 N. North West Hwy., Park Ridge, IL 60068-1400; (800) 323-2106.

If a child is not accepted for coverage under The Arc plan or if the child is too young to be considered for coverage, extending an existing insurance policy through COBRA may provide a temporary solution. The COBRA law requires an employer to continue health insurance coverage for a set period of time when employment ends or other disqualifying events occur. (Call COBRA at 202/219-8784 for more information.)

Since the most important aspects of the debate on health care reform seem to have shifted to the state level, it's essential that readers write to state legislators with their concerns about health insurance coverage.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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WHAT'S HAPPENING

Gianna, a VACC camper from Minnesota, enjoys the Florida sunshine on Miami's famous South Beach.

VACC Camp 1996

Plan ahead! VACC Camp '96, a free camp for children needing oxygen, tracheostomies, ventilators, BiPAP or CPAP—and their moms, dads and siblings—will be held in Miami, Florida, April 9–15, 1996. VACC Camp gives families a fun opportunity to socialize with peers and enjoy activities not generally accessible to children who are technology-dependent. Activities include field trips, swimming, games, arts & crafts, entertainment and special events. The application deadline is January 5, 1996. For more information, contact coordinator Cathy Klein, Ventilation Assisted Children's Center (VACC), Div. of Pulmonology, Miami Children's Hospital, 3200 SW 60th Ct., Ste. 203, Miami, FL 33155-4076; (305) 662-8222; (305) 663-8417, fax.

Morgan, a VACC camper from Florida, plugs his tracheostomy with a cap and takes a plunge in the pool with his mom.

Publications

• A new edition of *Fanconi Anemia: A Handbook for Families & Their Physicians* is now available. Fanconi anemia (FA) is a hereditary form of aplastic anemia, associated with cardiac, renal and skeletal abnormalities. Updated sections of the handbook cover bone marrow transplants, gene therapy and long-term clinical treatment. The book costs $2.50, including postage, in the U.S.; $5 elsewhere. FA Research Fund, 1902 Jefferson St., Ste. 2, Eugene, OR 97405; (503) 687-4658.

• *The Parent's Guide to Drug Treatment of Fragile X Syndrome* is a 100-page, detailed guide to medications commonly prescribed to help manage symptoms of fragile X syndrome. A reference page includes a rating for each drug's effectiveness, safety, convenience and cost. The book costs $25; all proceeds benefit fragile X research. FRAXA, P.O. Box 935, West Newbury, MA 01985-0935; (508) 462-1990; e-mail: fraxa@destek.net.

• *Facing Neurofibromatosis: A Guide for Teens* is a free booklet that answers common questions teens with neurofibromatosis (NF) may have about their condition. Send $1 (to cover postage) to the National Neurofibromatosis Foundation (NNFF), 95 Pine St., 16th Fl., New York, NY 10005. For more information about NF, call NNFF at (800) 323-7938, voice/TTY; or while traveling the Internet, visit the NNFF home page on the World Wide Web at http://nf.org/.

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Circle #92

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Circle #48

NEW PRODUCTS

TOOBERS & ZOTS

Toobers & Zots is a large-scale construction toy for children older than three. Using large tubes and shapes of soft foam, children can create animals, flowers, cars, crowns—almost anything their imaginations can conceive. Toobers are brightly colored foam tubes, designed on the concept of giant pipe cleaners, ranging in length from two to four feet. Zots are an assortment of stars, circles, squares, triangles and other shapes, which fit onto the toobers. The large-scale pieces encourage creative play for children with physical and visual disabilities. Toobers & Zots are available in 20-, 50-, 120- and 180-piece sets, each with bilingual English/Spanish instructions and a mesh storage bag.

HandsOnToys, Woburn, MA 01801

Circle # 195

WALKABOUT III

The Walkabout III is a mobile stander designed for use by adolescents. As the child steps forward, the stander provides spring-assisted lift and allows forward motion. The unit also provides lateral support to provide additional stability. It has an adjustable-width frame to accommodate growth. The unit can be positioned in front of a table and locked in place. Available options include handholds with forearm supports, no back-up brakes and shoulder pad supports.

Mulholland Positioning Systems, Santa Paula, CA 93061

Circle # 196

PANDA

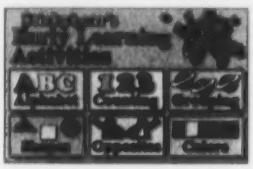
The Panda is a pediatric stroller and postural positioning system available in 10 models and three sizes—mini, midi and large. All models feature a lightweight, folding, aluminum-frame mobility base and a positioning insert with padded upholstery. The seating system features depth, width, back-height and pelvic/thigh adjustability. Standard equipment includes rear-wheel safety brakes and reclining and/or tilt-in-space seating. All models are approved for vehicle transportation.

Taylor Made Health Care, Gloversville, NY 12078

Circle # 197

STICKY BEAR'S EARLY LEARNING ACTIVITIES

Sticky Bear's Early Learning Activities is a software program designed to provide basic skills practice for children aged two to six. The program includes activities in six areas: alphabet, numbers, categories, shapes, opposites and colors. Each activity features animated graphics and sound effects, and can be used in one of two modes—structured play, which enables children to learn using prompted instruction, and unstructured play, which encourages learning through discovery. The activities are bilingual—English/Spanish. The program is available for both IBM-compatible (requires Windows) and MacIntosh computers.



Optimum Resource, Inc., Hilton Head, SC 29926

Circle # 198

CLEAR PLASTIC TRAY

The Clear Plastic Tray is designed to be inserted into a walker basket to carry a variety of small items. The tray features a large center compartment, a smaller compartment with rounded corners for carrying small items, such as pills or coins, and a round beverage holder for a glass, can or cup.

Maddak, Inc., Pequannock, NJ 07440-1993

Circle # 199

THE LISA REHA-BUGGY

The Lisa Reha-Buggy is a compact, folding push chair designed for children weighing up to 88 pounds. The chair features a lightweight aluminum frame, adjustable reclining seat, adjustable footrest and adjustable push handles that can be rotated toward one another to form a single push bar. The upholstery is available in a choice of Dino or Fantasy pattern. A variety of optional accessories and positioning aids are available. This chair has been tested and approved for vehicle transportation.

Taylor Made Health Care, Gloversville, NY 12078

Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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Circle #4

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National Christian Resource Center on Mental Retardation Bethesda Lutheran Home & Service
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See ad on page 62

Connecticut

CIB / Oak Hill School
120 Holcomb Street
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(203) 242-2274
Oak Hill School has been meeting the needs of children with multiple disabilities for over 100 years and believes that each student, regardless of the severity of his/her disability, can make progress. Our residential education programs are community-based and provide an environment that is both supportive and challenging.
See ad on page 93

Florida

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Miami, FL 33173
(305) 271-3232
See ad on page 93

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Goldenrod, FL 32733
(407) 671-7060

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Agape Village
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See ad on page 63

Annandale Village
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See ad on page 93

Kansas

Heartspring
2400 Jardine Drive
Wichita, KS 67219-4699
(316) 262-8271
Heartspring serves students ages five through 21 who have multiple disabilities and communication disorders. We serve residential school and day-only students. Outpatient assessments, short-term treatment programs, and hearing center services are also offered.
See ad on page 81

Kentucky

The Stewart Home School
Box 20
Frankfort KY 40601
(502) 875-4664
Progressive education, home environment for mentally handicapped children and adults. Multiple recreation and activities. Year round program. Est. 1893. Call or write for brochure.
See ad on page 93

Maine

Bancroft
Lighthouse Road
Owl's Head, ME 04854
(207) 594-7261
Year-round programs and vacation options for people with developmental disabilities/head injury.
See Bancroft in New Jersey section.

Massachusetts

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 01236
(413) 528-2523
For children and adults who have severe neurodevelopmental disabilities and complex medical problems. Private, non-profit residential setting in the Berkshires, offering a comprehensive approach to each individual's well-being with integrated educational, medical and rehabilitative services.
See ad on page 77

Crystal Springs School
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Assonet, MA 02702
(508) 644-3101, Ext. 328
Established in 1953, Crystal Springs offers licensed home-like residences; and approved private school; full rehab. program; and 24-hour licensed nursing coverage designed to meet the needs of medically fragile, multi-handicapped children and young adults, birth–22 yrs.
See ad on page 78

Cotting School
453 Concord Avenue
Lexington, MA 02173
(617) 862-7323
Cotting School welcomes boys & girls ages 3-22 with physical, medical, learning & communication disabilities. We offer individualized academic, pre-vocational and social experiences to build confidence & enhance students' self esteem.

Evergreen Center
345 Fortune Blvd.
Milford, MA 01757
(508) 478-5597
Residential school for students who are developmentally disabled and require education or assistance in self-care, community living, adapted communication, mobility trainingor behavior control due to psychiatric/behavioral, medical or therapeutic needs. An intensive programis available for severe maladaptive or self-injurious behavior.
See ad on page 79

Ivy Street School
Brain Injury Program
200 Ivy Street
Brookline, MA 02146
(617) 732-0224

Latham School; R.R.C.I.
P.O. Box 1879
1646 Main Street
Brewster, MA 02631
(508) 896-5755
Special education / residential school for girls ages 8-22 with mild dev. delays and ED/ BD
Contact: Shirley Landers-Pfautz

League School of Boston
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260
See ad on page 22

The Learning Center
411 Waverley Oaks Road
Waltham, MA 02154
(617) 893-6000
Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities. 12 mo. day/residential.
See ad on page 93

The New England Center for Autism
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(508) 481-1015
Day/residential school for children with develop. disabilities, behavior disorders age 3–22. Integrated preschool, inclusion services. staff intensive program., functional activity based curriculum., supported employment in modern school and group homes.
See ad on page 74

New England Villages, Inc.
664 School Street
Pembroke, MA 02359
(617) 293-5461
Exceptional private community for MR adults offering a range of residential options, vocational, recreation and social opportunities.
See ad on page 57

Riverview School
551 Rt. 6A
East Sandwich, MA 02537
(508) 888-0489/ Fax (508) 888-1315. Residential co-ed program serving adolescent 11-20 who have a primary diagnosis of a learning disability & function cognitively between 70-100.

St Coletta's of Massachusetts Cardinal Cushing School and Training Center
400 Washington Street
Hanover, MA 02339
(617) 826-6371
See ad on page 8

New Hampshire

Crotched Mountain Rehabilitation Center, Inc.
1 Verney Drive
Greenfield, NH 03047
(603) 547-3311, ext. 235
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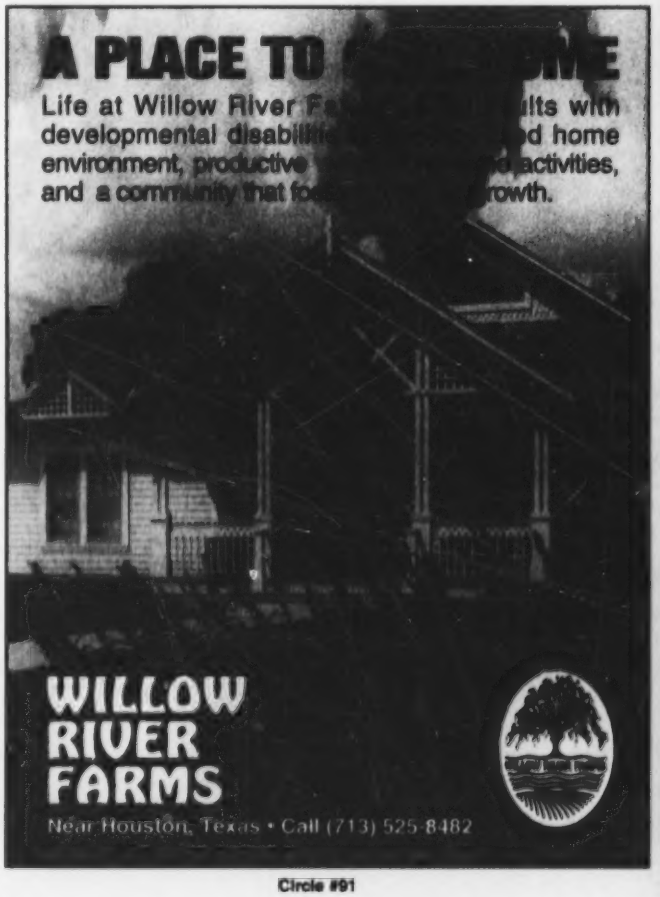

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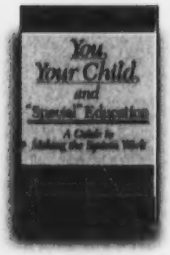

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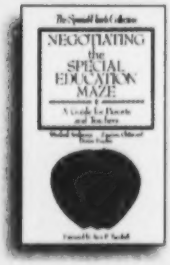

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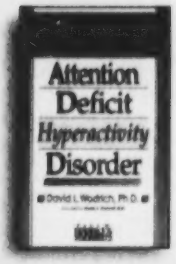

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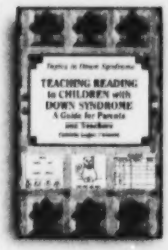

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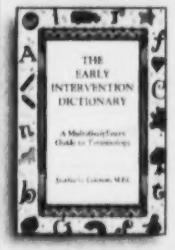

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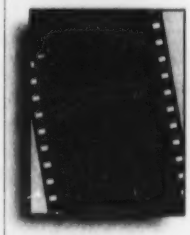

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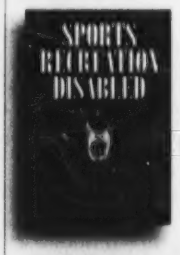

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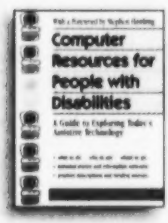

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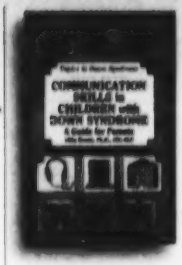

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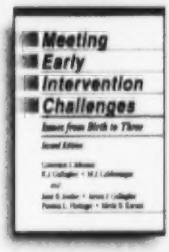

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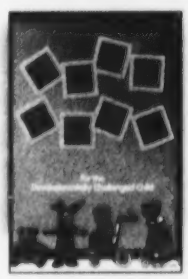

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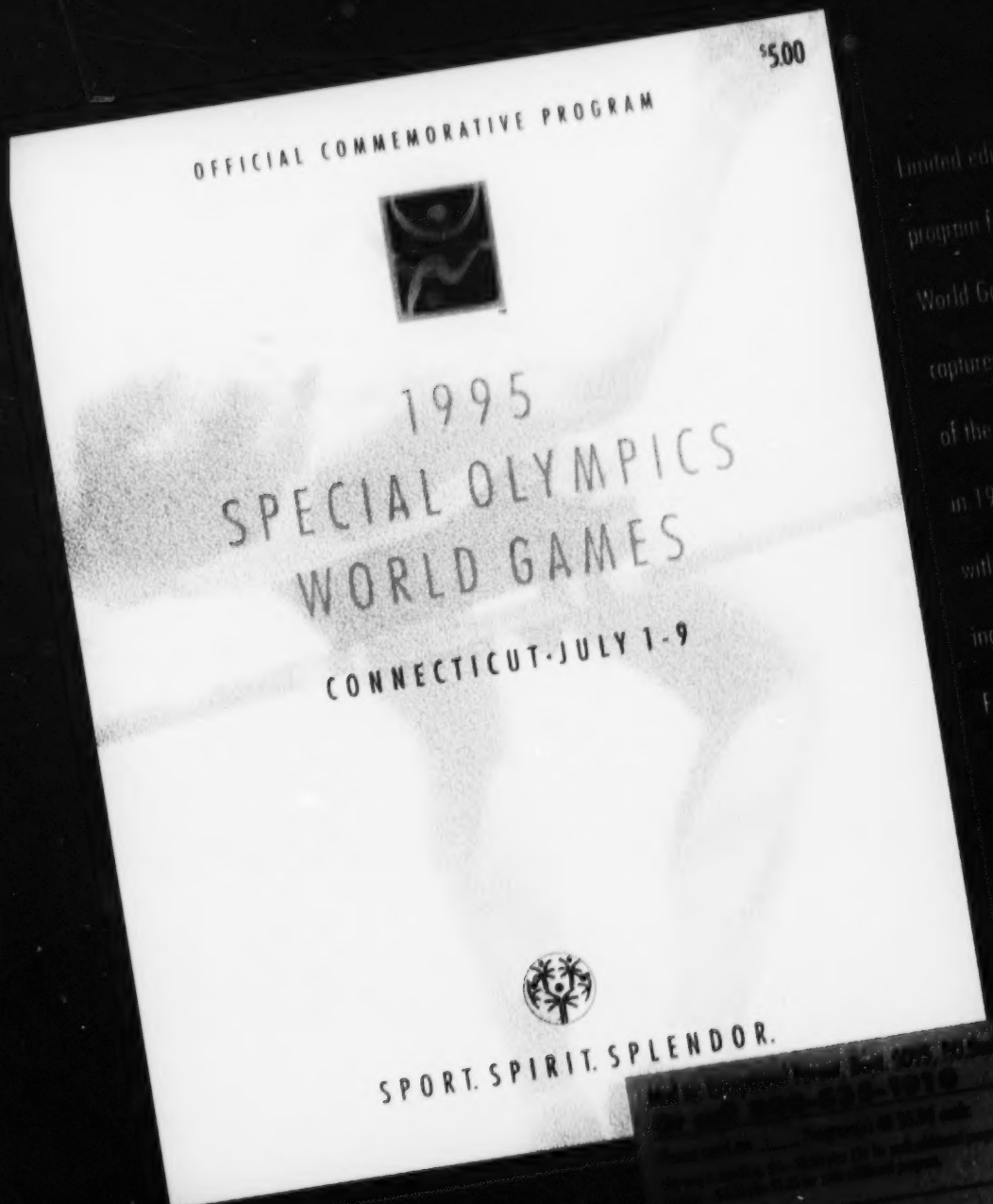

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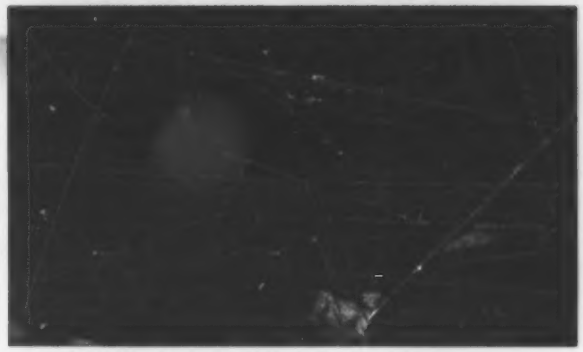
by Kristina Ferrini



Two of Kristina's classmates meet her brother, Joey (right).

Last year, my fifth-grade teacher, Mrs. Jenkins, had our class read a book called *Welcome Home, Jellybean*, by Marlene Fanta Shyer. The book is about a dad and mom who put Gerri, their daughter with mental retardation, in a training school. Eventually, they are able to bring Gerri home for good, but they know things will be different now.

Like most 14-year-olds, Joey just loves pizza!

In the book, Neil, Gerri's younger brother, tells about how the family never gets enough rest because Gerri bangs her head on the wall at night. Gerri sits on top of the piano, and her dad always gets mad about that. Every time someone comes into the house, Gerri runs up and hugs the person. The mom is always busy. The dad leaves, because Gerri gets to be too much for him. Neil decides to live with his dad, but then he comes back home.

Since Gerri, the character in the book, has disabilities, I thought of my 13-year-old brother, Joey, because he has disabilities, too. I told my mom about the book. I brought the book home and my mom read it. Together, Mrs. Jenkins, my mom and I decided to have my brother visit my class.

The day before Joey's visit, my mom came into my classroom to answer questions from the kids. They asked a lot of questions: How did you find out Joey had disabilities? What is his favorite sport? Does he ride a bike? What are his strengths and weaknesses?

The next day, when Joey came to my class, he seemed nervous. I was nervous, too, but I did well. Joey read to the class and showed how he could do addition. Then some kids helped him color. The class enjoyed Joey's visit. **EP**

Kristina Elizabeth Ferrini, 11, is a sixth-grader at Zellers Elementary School in Strongsville, Ohio. She enjoys violin and piano lessons. Her other hobbies include crafts and gymnastics. Joey, now 14, has cerebral palsy, mental retardation, epilepsy and asthma. Joey attends a special education program at Albion Junior High School, also in Strongsville.

To order ***Welcome Home, Jellybean,*** send a check or money order for $3.95 plus your state's sales tax to Simon & Schuster, 200 Old Tappan Rd., Old Tappan, NJ 07675-7095. Include the book's ISBN number: 0-689-71213-8. This book is also available from Exceptional Parent Library (800/535-1910). Order number: SS126OD

Mom's turn:

Kristina told me she thought I might enjoy reading Welcome Home, Jellybean because it was about a girl named Geraldine, who was a lot like our Joey. Kristina was right. The author painted a vivid picture of life with a child who has a disability. A few times, I found myself reaching for a tissue because the challenges and frustrations faced by the family in the book seemed as real as they can be in our own family.

Life with a child like Joey takes a lot of love, time, patience and understanding. We often realize that other families do not always see things from the same perspective. We hope to show everyone that we love Joey and are committed to helping him in any way that we can. Our family is a team.

I enjoyed the opportunity to spend two days in Kristina's classroom. The day before Joey's visit, I spent an hour answering any questions the children cared to ask—and they asked a lot of good ones: How did you find out Joey had a disability? How did it happen? How does Joey learn? Why can't he talk very well? What will he do when he's finished with school?

I was able to share what it is like raising Joey: the stress involved in meeting his physical and medical needs, and the frustrations of dealing with others who are impatient with him because they do not understand his limitations, the difficulties understanding what he tries to say—as he repeats the same phrase over and over, even when we don't "get it." But I was also able to share the joys: getting a big hug, watching him eat a whole pizza while saying, "Joey's favorite," knowing that Joey's grandparents, aunts, uncles and cousins really like him, just the way he is.

When Joey visited Kristina's classroom, all the children, as well as the teacher and principal, made him feel welcome. They included him in the things they were doing, and he showed them some of the things he can do.

We had a wonderful time learning about each other. I hope the children gained a deeper understanding of someone who may have limitations, yet enjoys a lot of the same things they do. It was a fun way to share the reality of our family's life with Joey and make the book more "real" to the children.

—Cindy Ferrini

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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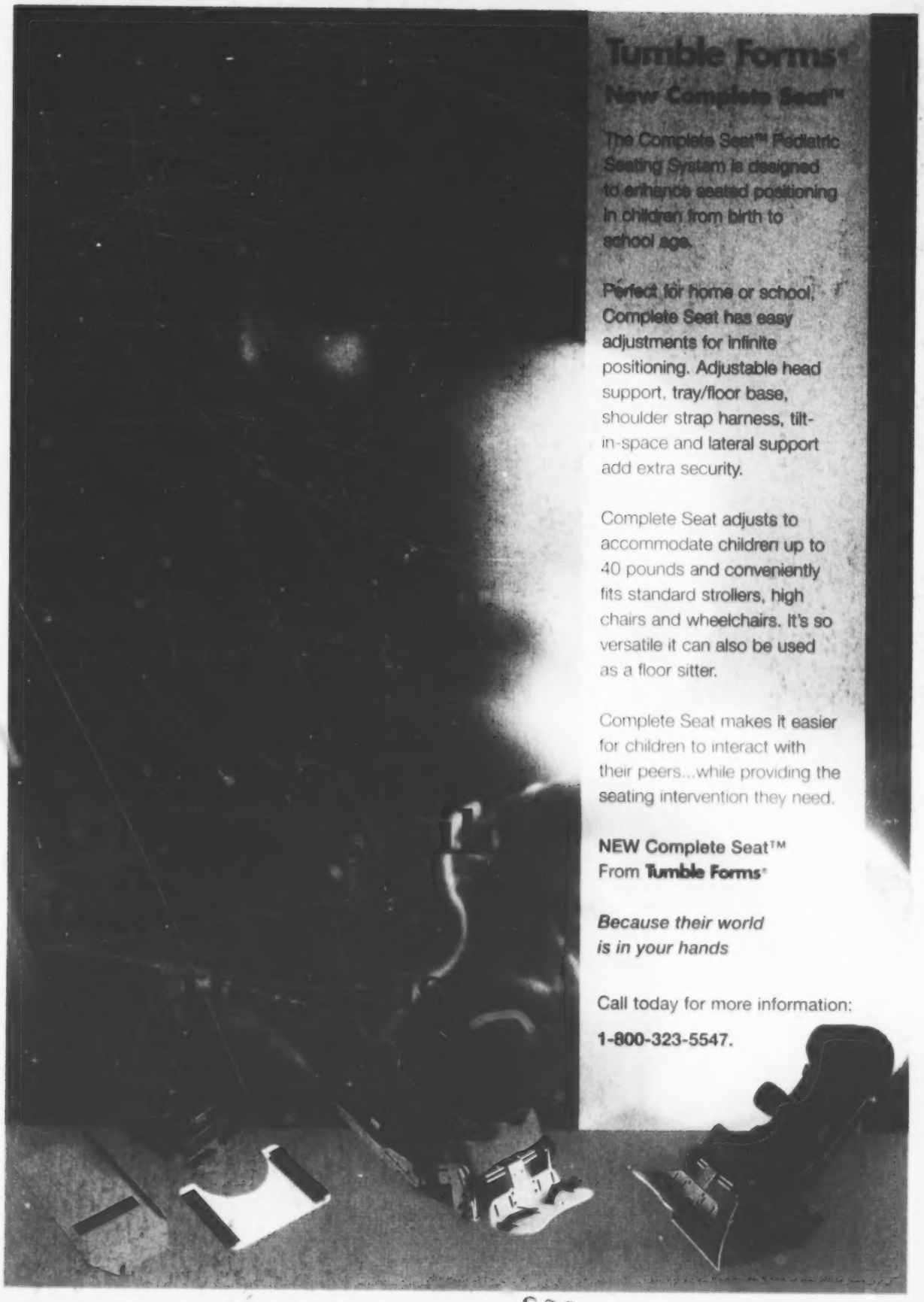
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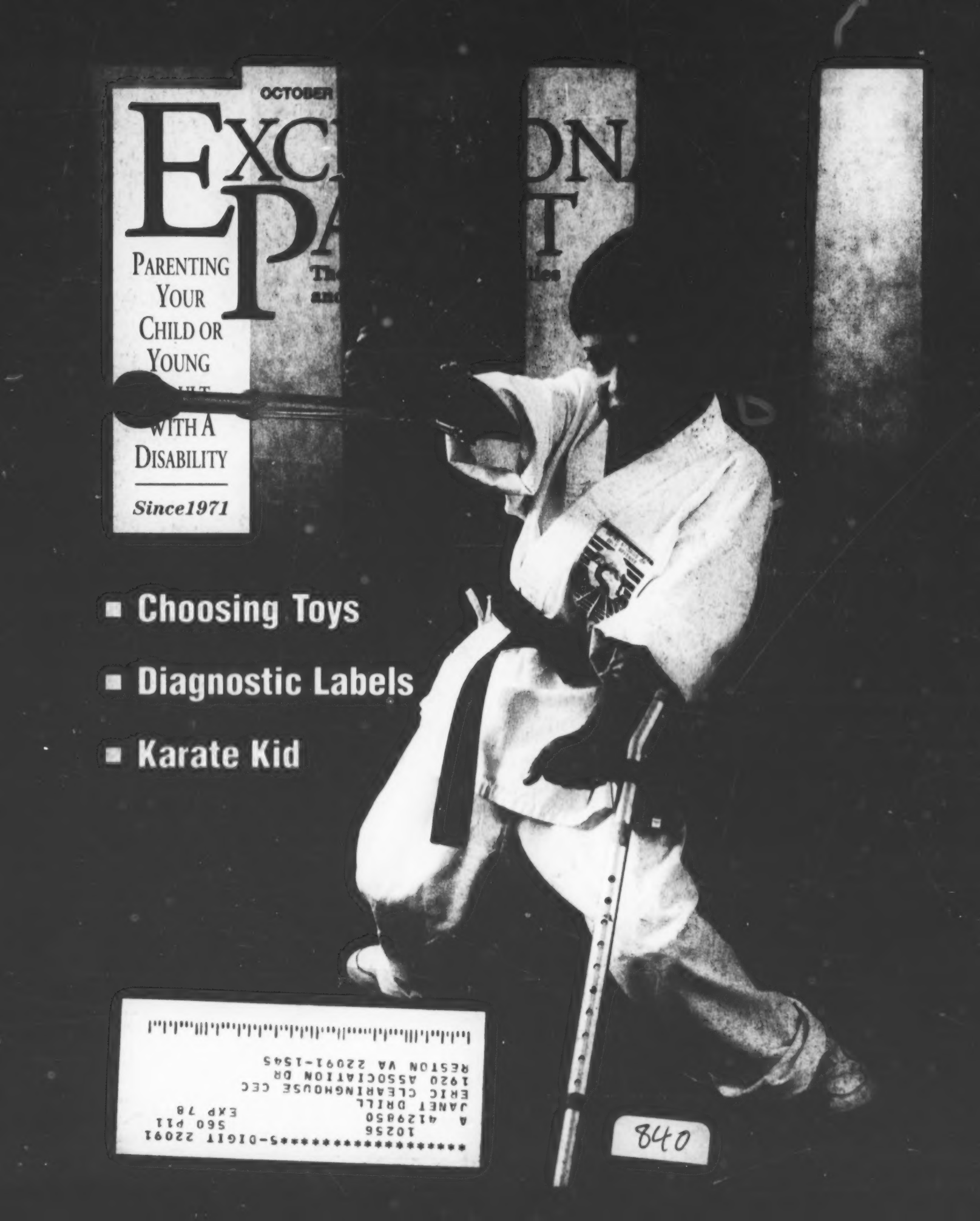
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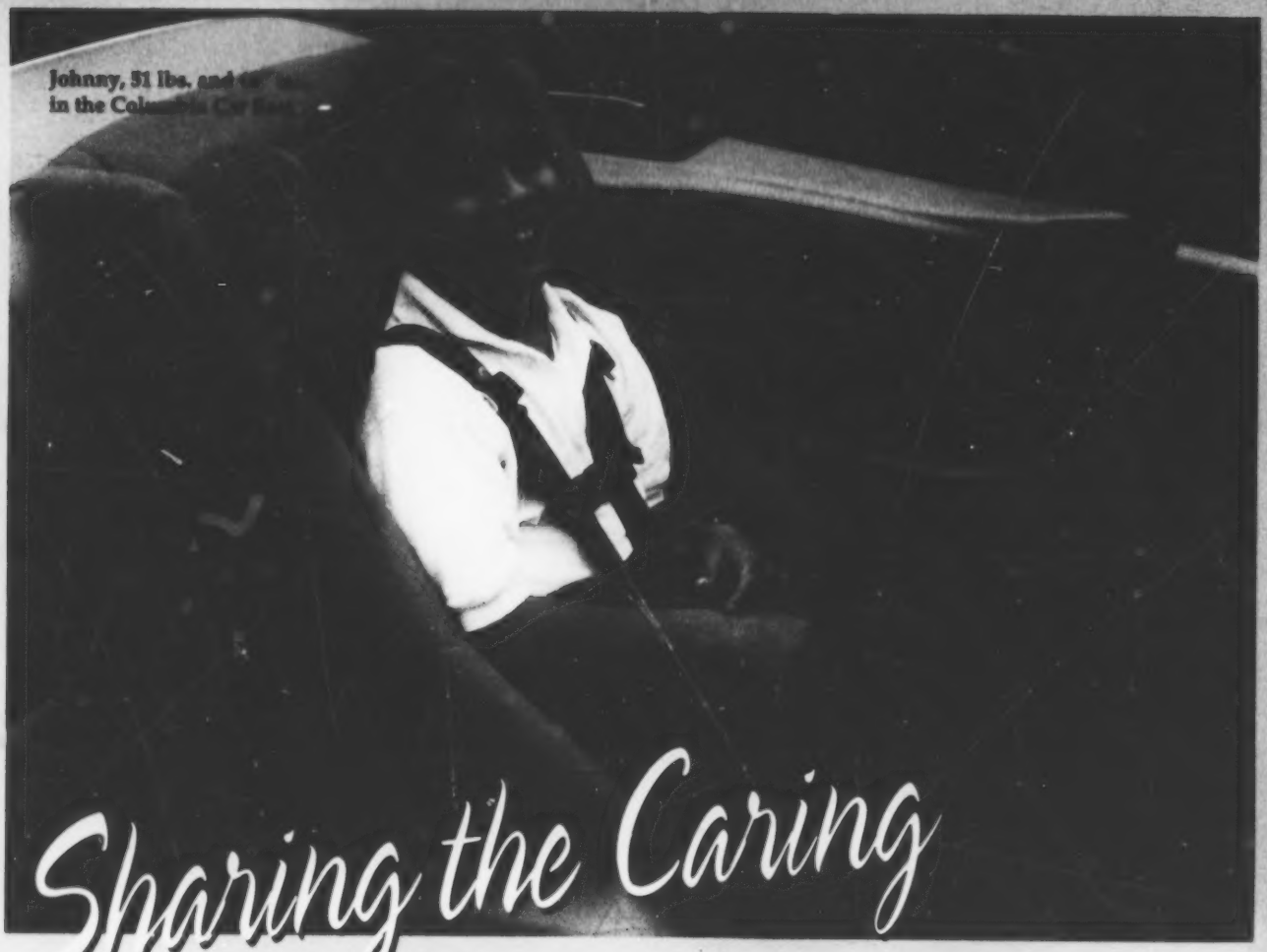

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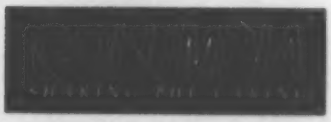

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EXCEPTIONAL PARENT

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971

The Magazine for Families and Professionals

OCTOBER 1995 VOL. 25, ISSUE 10

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Cover: Barry Atkinson, 11, studies karate at United Studios of Self-Defense in his hometown of Huntington Beach, California. Well on the way to his goal of attaining a black belt, Barry currently holds the rank of orange belt, and last spring, won a trophy competing in his first karate tournament.

Barry has spina bifida with the Arnold-Chiari malformation of the brainstem and cerebellum, hydrocephalus, a gastrostomy-button and a tracheostomy. He lives with his foster parents, Ann Belles and Mark Andrews, and is a fifth-grader at Moffett Elementary School in Huntington Beach. Barry's article, "The Karate Kid," appears on this issue's Children's Page. Photo: Alex Garcia.

BPA

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EDITOR'S DESK

Toys!

We had so much fun preparing previous features on toys (October 1994 and June 1995) that we've once more invited Joanne and Stephanie Oppenheim to help our readers prepare for holiday shopping by sharing suggestions for ordinary, off-the-shelf toys that children with disabilities can enjoy with little or no adaptation. But before you hit the toy store with wallet in hand, Annette Heim's account of her son's best-loved toys ("Rubber Balls, Toy Cars and Art Supplies") will remind you not to overlook some of the old favorites.

STANLEY D. KLEIN, PH.D.

Diagnostic labels

When parents first hear the clinical diagnostic terms used to describe a child's disability, the words can be terrifying. Sadly, these diagnostic labels are sometimes used to lower expectations or exclude youngsters from opportunities. But as Dr. Karen Levine's article "Beyond Labels" illustrates, knowledge of specific disabilities can be used to help a child draw on his or her strengths while overcoming or working around challenges.

President's Committee on Mental Retardation

In early September, I traveled to Washington, DC to attend the 1995 National Collaborative Academy on Mental Retardation sponsored by the President's Committee on Mental Retardation. Although many in attendance were concerned about the political climate, including potential changes in legislation and/or cuts in funding, the active participation of "self-advocates"—adults with mental retardation—speaking for themselves and working collaboratively on planning teams made this a truly inspiring meeting. In November, the "Role Models" department will feature one of these young self-advocates.

The growth of self-advocacy illustrates a changing perspective about community services for adults with mental retardation and/or developmental disabilities—a perspective that focuses on individuals and encourages self-determination. Reports at this conference demonstrated many ways in which individual states have moved beyond slogans to thoughtful action. A number of new programs are enabling adults to make choices about their own lives. For example, more and more adults with disabilities are being invited to serve on planning committees, and adults with mental retardation are becoming home owners and taxpayers.

Also at the conference, Bob Williams, commissioner of the Administration on Developmental Disabilities, addressed current concerns about the political atmosphere in Washington. Thanks to Bob's quick work with us, we were able to adapt his stirring address, which he delivered with his augmentative communication device, as a guest editorial in this issue (see page 45). And for still more on the political scene, see *Networking* on page 49.

While in Washington, I also learned that Speaker of the House Newt Gingrich has established a House Task Force on Disabilities. For more information, see *What's Happening* on page 64.

Let's celebrate!

In 1996, we will mark EXCEPTIONAL PARENT's 25th birthday! Exciting plans for extra-special issues are in the works—we welcome your ideas and suggestions. We are even exploring the possibility of a trip for families to a fun place like Walt Disney World. This would take place in October 1996. We need to hear from readers who would be interested in joining us, so we can determine the best possible prices for travel and accommodation packages. Please write to Disney Trip, EXCEPTIONAL PARENT, 209 Harvard Street, Ste. 303, Brookline, MA 02146; (617) 730-9742, fax.

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For subscription and advertising information, see page 58.

BPA

MOST PARENTS OF BED WETTERS THINK THERE IS VERY LITTLE THEY CAN DO TO HELP.

Some 3 million children, 10% of all kids between 5 and 10, wet the bed twice a week or more. If your child is in school, chances are at least two of his classmates are in the same leaky boat. No child should ever feel alone with this problem. But, of course, they do.

The good news: More is known than ever before that can help. Once, the only sure cure was time. 99.9% of our children leave this problem in the dust as they grow. And now there are some new ways to give time a hand.

THE BEST BEGINNING

For starters, pediatricians know a lot more about the causes of "enuresis" (that's the official medical name for it) than they used to.

Doctors today deal with this problem all the time. They have new techniques and sometimes medicines that can help manage bed-wetting, if not eliminate it altogether.

And now (finally!), there are pants you can buy that can make a real difference at your house, every night and every morning. Your child will still wet. He can't help it. But from now on, that doesn't have to mean he has to wet the bed.

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LETTERS

Appreciates definitions

I just wanted to let you know I really appreciate your recent efforts to explain more about disabilities mentioned in the magazine, particularly in *Search and Respond*. I'm always interested in learning more about the various "realities" people live with as "exceptional parents," but am usually too lazy to go look up information about disabilities I am not familiar with. And frankly, some of these conditions are so rare, I wouldn't be able to find them in the books I own anyway. Your extra efforts in this regard make your magazine much friendlier and much easier to read.

J.W.P., North Carolina

False Accusations of Abuse

Writing in the August 1995 issue, B.T. of Connecticut responded to the May 1995 article on facilitated communication by saying, "I would rather see someone falsely accused of abuse than see a guilty person not be accused."

I am appalled by this statement! What an attitude—"shoot them all and let God sort them out." Far too many people have been falsely accused of abuse; their reputations have been ruined, their lives shattered. In B.T.'s philosophy, they are expendables.

Contrary to B.T.'s belief, we cannot assume children are always truthful. We must consider the possibility that a child may be imagining something, or even outright lying.

I've been the victim of a person who needed to invent this type of situation.

Tom Carten
Wilkes-Barre, Pennsylvania

Ketogenic Diet

I have read with great interest your coverage of the ketogenic diet for the control of seizures (*Letters*, June 1995 and *Ask the Doctor*, July 1995). Your Editor's Note following the letter in the June issue states that the diet is "used most often with children aged two to six." Although it may be true that some older children will not like the diet's restrictions, I think most would be willing to try anything for the possibility of being seizure-free and medication-free for life.

In July's *Ask the Doctor* column, Dr. Hirsch says, "This diet should not be the first choice among options for seizure control..." Why not? I wish I had known about the ketogenic diet four years ago, before we went through four medications, thousands of dollars and too many neurological tests to count. Why would any parent choose a lifetime of seizures, medications and blood tests over two to three short years of following a strict diet?

My nine-year-old daughter, Renee, began the ketogenic diet on June 27, 1995. I can't even begin to tell you about the wonderful changes that have resulted. Best of all is *no more seizures!* Renee is never hungry or thirsty; in fact, I have to keep reminding her to drink all of her allotted liquid.

Last week, I asked Renee if she wanted to go back to eating all the things she ate before. Her reply was an emphatic, "No way! I want off these pills!"

I believe every parent of a child with epilepsy should be given the opportunity to try the ketogenic diet. It should be the duty of every neurolo-

continued on page 6

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▸ *To empower parents and professionals by providing practical information and emotional support.*

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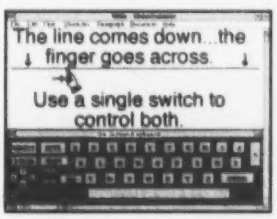

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Circle #80

LETTERS

continued from page 4

gist to inform patients of *all* treatment options for seizure control, not just "drug therapy."

In addition to the resources listed in July's *Ask the Doctor,* I would also like to tell parents about the *Keto Klub Newsletter,* which provides information and helpful ideas about the ketogenic diet.

Lisa Smith
St. Joseph, Michigan

DR. HIRSCH RESPONDS: I am always happy to hear about successful therapy for seizure disorders. In many individuals with seizures, a single anticonvulsant will be effective, and have few or no side effects. For those individuals, this option for seizure control would be safer and easier to manage than a ketogenic diet. However, if a seizure disorder appears very complicated or intractable (hard to control)—and this should become clear within two years—a ketogenic diet would be a reasonable therapeutic option.

EDITOR'S NOTE: Subscriptions to the KETO KLUB NEWSLETTER, published quarterly, cost $20 in the U.S., $25 in Canada and $30 for other countries. For a free sample copy, send a self-addressed envelope with a 32¢ stamp to KETO KLUB NEWSLETTER, 61557 Miami Meadows Ct., South Bend, IN 46614.

Fragile X Syndrome and Genetic Counseling

I was so excited to see the June 1995 issue in which the *Ask the Doctor* column dealt with fragile X syndrome. It seemed like a giant step forward in our goal to increase public awareness of the leading cause of inherited developmental disability. But two months later, reading the article "Genetic Counseling" (August 1995), my heart sank. In that article, a clinicial geneticist listed the types of families who might benefit from genetic counseling. But that list of candidates for counseling did not include families with a history of unexplained mental retardation or autism.

The genetic counselors and geneticists who advise our parent group would certainly disagree. Please set the record straight and let's take another giant step forward together.

Mary Seward, President
Fragile X Association of Southern California

EDITOR'S NOTE: Thank you for your letter. Our experts agree with you.

Tell us about...

... your child's experiences (both good and not so good) at summer camp.

What type of camp(s) has your child attended? How did you choose the camp(s)? If your child has attended a "regular" camp, what adaptations were made?

Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

847

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SEARCH

Rh Incompatibility

Surely, there has to be another family in this country who can relate to our situation! My husband and I have incompatible blood types due to the Rh factor. I am Rh negative; he is Rh positive. We have two children. Throughout both pregnancies, I received excellent prenatal care, including Rhogam shots to prevent any sensitization between my blood type and my child's blood type should they have inherited their father's Rh positive blood (both did). We thought we were safe until 38 weeks into my second pregnancy, I found myself being rushed off for an emergency C-section.

My daughter, Rebecca, spent six and a half weeks in the NICU with serious problems caused by Rh incompatibility, also known as hemolytic disease of the newborn or erythroblastosis fetalis. Her spleen and liver were enlarged, and because her liver was not functioning well, she had hyperbilirubinemia (jaundice caused by excess bilirubin in the blood). Things got so bad, we had her baptized.

Now Rebecca is 21 months old and has cerebral palsy. She can't do anything for herself. Her independent sitting is poor, and she can't stand, crawl, creep, walk or talk. Doctors told us that because I'm now producing antibodies to Rh positive blood, any future pregnancies will be affected by this disease.

We know that prior to the availability of Rhogam, more children were affected with Rh disease. Does anyone know them? Or is anyone going through this now? We'd love to talk to them because we have a lot of questions.

G.C. & S.C., Connecticut

Congenital Muscular Dystrophy

Our four-year-old daughter, Olivia, has been diagnosed with congenital muscular dystrophy. She has generalized gross motor weakness, but her fine motor skills are normal. At birth and throughout infancy, Olivia appeared average in every way but did not achieve milestones. She could not hold her head up, crawl or use her arms or legs to support herself. By nine months, if placed in a sitting position, Olivia was generally able to maintain that position, but if she fell over, she could not get up.

At the age of 13 months, a blood test showed that she had extremely high levels of CPK (creatine phosphokinase) in her blood. An EKG (electrocardiogram) and EEG (electroencephalogram) were normal. An MRI (magnetic resonance imaging) of the brain showed some anomalies. Finally, a muscle biopsy was done. Although the results were not clear-cut, doctors concluded she had congenital muscular dystrophy.

At 18 months, Olivia began physical therapy. She can now crawl a short distance and is starting to climb on and over low objects. She also scoots on her rear end. She uses a manual wheelchair outside our home and in preschool. She is potty-trained, intelligent and happy.

Olivia's doctors cannot tell us whether she will continue to progress or start to regress. They cannot tell us if she will be able to walk on her own. They cannot tell us the chances of having another child with this condition.

We are looking for parents whose child has the same or a similar diagnosis. We want to know how they approach day-to-day life, what sort of school their child attends and whether they have had other children—"normal" or with the same diagnosis.

C.D., California

Undiagnosed

I'm interested in finding someone who may know what's wrong with our son, David. He is a three-year-old, white male with hypotonia (low muscle tone), scoliosis (curvature of the spine), cataracts and nystagamus (involuntary, rapid eye movements). The results of all the tests and muscle biopsies done have come back negative.

David seems to understand simple commands, such as "give me a kiss." But over the last six months he stopped eating solid foods and cut back on the amount of milk he would

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If you know a child who might benefit from Heartspring's programs, or if you would like to know more about the new campus, call today. Together we can build a brighter future for your child.

Photo courtesy of Madeline McCullough and Ric Wofford

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Circle #3

SEARCH

continued from page 8

take. Now he is continuously fed by NG-tube (a feeding tube that goes through his nose to his small intestine). But it doesn't seem to be working—he weighs only 20 pounds and continues to lose weight. He is also regressing in other skill areas, particularly gross motor skills. He cries so much during therapy sessions that I wonder if it is worth putting him through the pain. Otherwise, he is a very good-natured child.

D.C., Indiana

Toilet Training Equipment

I am an occupational therapist in a public school. I am looking for a source for "high-tech" toilet-training equipment (for example, moisture-activated switches that can be placed in underwear and potty chairs that play music when a child urinates). Such equipment would allow for immediate reinforcement of the desired "behavior" and minimize time spent on the potty chair. I would appreciate any leads on these types of items.

S.S., Illinois

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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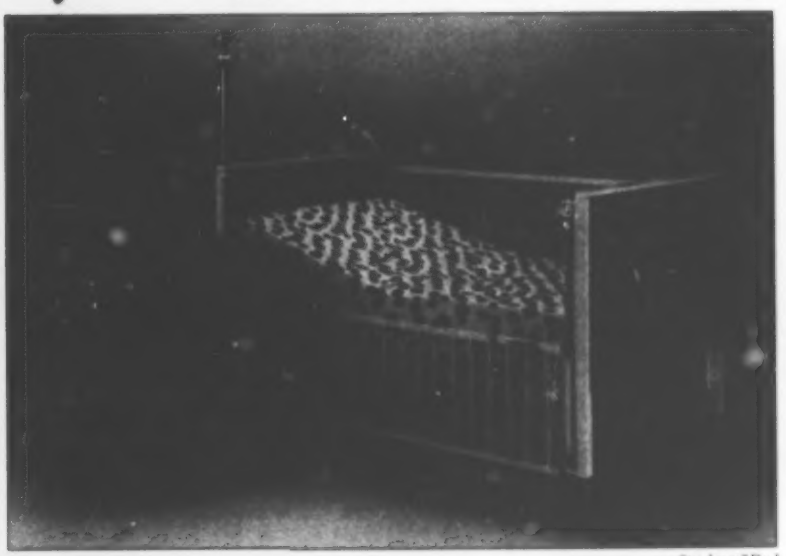

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Circle #98

RESPOND

Self-stimulation and Smearing

K.D. (July 1995) has a 10-year-old daughter, Aimee, who has severe mental retardation, is nonverbal, has an uncontrollable seizure disorder and wears diapers. K.D. was looking for advice on controlling Aimee's habit of "masturbating" until she had a bowel movement, then "body painting" with her own feces.

I am an occupational therapist (OT) who has worked with another child who smeared feces. Here are suggestions that worked for us:

• *Set up a routine that could substitute for the smearing:* Give her body rubs with body oil, and hand rubs with strongly-scented oil or lotion. Be sure to do the substitute "treatment" frequently and regularly, so it is predictable to Aimee.

• *Use tight (lycra/spandex) work-out clothing over Aimee's diaper:* Footed tights plus a one-piece "unitard" on top should make it difficult to get fingers inside the diaper. With a cloth diaper underneath, this outfit could also be used for swimming.

• *At swim-time it would not seem inappropriate for Aimee to wear a rubber inflatable ring with a sling seat, the type used by small children.* Perhaps your OT could help make it snug enough that Aimee has trouble reaching under or around it. This ring could also be used at home during playtime, but not in bed.

We have had the most success by expecting any habit, such as self-stimulation, to be under control while the child is with others, rather than expecting it to be eliminated at all times.

J.O., Connecticut

Waterbed?

D.S. (July 1995) wonders if her one-year-old daughter, who has spastic quadriplegic cerebral palsy and limited movement, is comfortable sleeping on a flat mattress. D.S. was considering the purchase of a waterbed and wondered if other parents could share their experiences.

Our son is 10 years old and has multiple disabilities. He is deaf and blind, and has hydrocephalus, a seizure disorder and spastic quadriplegic cerebral palsy. When Michael was 18 months old, he began banging his head in his crib. At that point, we decided to buy him a waterbed. We hoped it might stop his head banging, and we also thought it might be more comfortable and provide him with different sensations.

The bed we purchased had a semi-waveless mattress, which allows only a minimal amount of motion. But soon after getting the bed, Mike learned how to move around with the small movements of the "waves." Within six months, he began crawling.

Today, Mike can walk with assistance and can pull himself up to stand. His multiple disabilities limit him greatly, but all things considered, he is doing quite well.

J.R., Illinois

■ We have adopted three children. All three have spastic quadriplegic cerebral palsy.

Our two older children came to us when they were less than one year old; neither had any movement at all. We immediately

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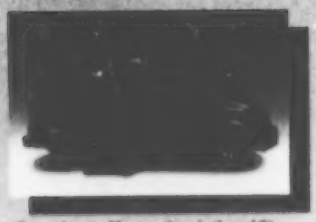
B R A U N



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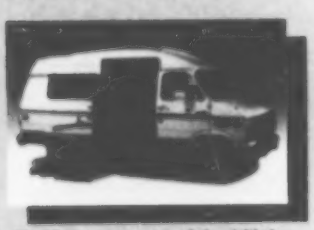

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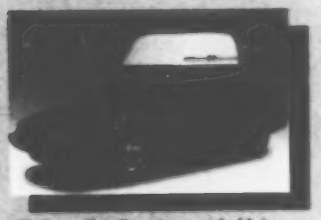

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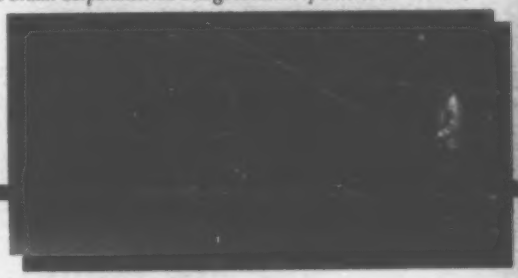

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Circle #112 856

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put them in free-flow waterbeds, watermattresses that do not control "waves." They both benefited greatly from the immediate reinforcement they received for even minimal movements. Now, our 16-year-old son "scoots" all over our home and our nine-year-old son rolls where he wants to go. Neither one has significant contractures or scoliosis. I believe the integrity of their musculoskeletal systems is a direct result of the movement that was encouraged by use of their waterbeds at night, along with proper, secure positioning during the day. Our newest child, a one-year-old, has been in a waterbed for six months, and is now starting to push her foot against the side to rock herself.

R.R. & P.R., Florida

■ Even before our child was born, we knew he or she would sleep on a waterbed. I was the owner of a bedroom store specializing in waterbeds.

Our son was born with spastic quadriplegic cerebral palsy. Because I worked in the industry, I was able to have a custom-built frame and watermattress made for him. Because we worried about him rolling out of bed, we installed a clear Plexiglass wall on the side—about 10 inches higher than the top edge of the frame. While protecting him, it allowed him a clear view of the room and everything that was going on around him.

We believe that the warmth provided by the heated waterbed helps his muscles to relax while he is sleeping. A waterbed is not a cure-all; he also attends occupational and physical therapy sessions and is involved in a horseback-riding program.

Over the years, we've also noticed that our son sometimes develops pressure sores after hospital stays. This has never happened at home where he uses his waterbed. In the waterbed, he can sleep all night without needing to be turned.

I am a member of the board of directors of the National Waterbed Council (236 Rte. 38 W., Ste. 100, Moorestown, NJ 08057), which can provide additional information about waterbeds. The Council's sister organization, the Flotation Health Care Foundation (5757 W. Century Blvd., #512, Los Angeles, CA 90045) can help provide waterbeds to individuals who need one for a medical reason, but lack the necesary financial resources. You may write to these organizations for more information.

I would also like to offer my assistance to any EXCEPTIONAL PARENT reader. I can provide information or referrals to helpful waterbed dealers.

D.M., Indiana

EDITOR'S NOTE: Readers wishing to take D.M. up on his offer of assistance may write to him c/o EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. On the lower, left-hand corner of the envelope, please include the words, "ATTN: Waterbeds." We will forward all letters to D.M.

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For more information on the Companion Seat® or other Braun mobility products, call us today at 1-800-THE LIFT. We will give you the name and location of distributors in your area.

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Circle #113

Familiar Faces

Six-year-old **Jeremy Latta** (right) is ready to trick-or-treat 'til the cows come home! Jeremy, shown here with sister **Ashley**, 4, loves cows. "The one sound he can make clearly is 'moo,'" explains his mother, **Janice**. "When he put on his costume, he absolutely beamed with joy." Jeremy, of Plymouth, Massachusetts, has chromosome XYY, autism and a seizure disorder.

Five-year-old buccaneer **Rachel Leanna Tung**, of San Francisco, California, paused from her pillaging to smile for the camera. Rachel, now 7, has undiagnosed developmental delays and low muscle tone, and was born with a cleft palate. She attends Ulloa Elementary School in San Francisco. "She has lots of friends there," writes Rachel's mom, Linda. "She really enjoys school."

Elyse Ritter, 2, (left) of Columbia, South Carolina, and her five-month-old brother, **Adam**, celebrated Halloween 1992 in style. "We think they made adorable pumpkins," write their parents, Stephen and Frieda. Adam liked life as a pumpkin so much, he stuck with that theme the following Halloween, but Elyse decided to branch out and don the garb of Snow White. The Ritters describe themselves as "big fans" of EXCEPTIONAL PARENT. Elyse has cerebral palsy.

Young dragon **Brendon Kirsch** of Sherman Oaks, California, carefully guards his bag of Halloween goodies. Brendon, 17 months, has cerebral palsy. "He enjoyed strolling through the local mall in his costume," writes Mom Marcy. She adds that the scaled suit was "lovingly made" by his babysitter, Hilda Cabrera, of Van Nuys, California.

Jason Montgomery, 14, of Pemberton, New Jersey, takes his Halloween costume, the "SS Jason," on its maiden voyage. Jason's mom, Carol, writes that her son's wheelchair float, inspired by EXCEPTIONAL PARENT's September 1994 article "Halloween Magic," was the first of its kind at his school—Burlington County Day Training Center in Mt. Holly, New Jersey—and a big hit with teachers, who found it easy to wheel him from class to class for trick-or-treating. Jason has Angelman syndrome.

Would you like to share a favorite candid snapshot or slide *of your child and/or family with other readers of* EXCEPTIONAL PARENT*? Send it to: Readers' Photos,* EXCEPTIONAL PARENT*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

859

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Camryn, 13 months, enjoys a walk in the rain with Dad.

Accepting Pinocchio

Maybe we can learn to be "real" parents

by Gregory Burns

Have you ever been taken by surprise by your emotions? It happened to me recently, when I saw a promo for the movie *Pinocchio*. All of a sudden, I found myself dealing with a whole set of feelings I had packed away and pushed to the back of my "emotional garage"—one of these days, I've got to clean that place out!

That movie promo brought me back to the moment my wife and I learned that one of our twin daughters had a chromosomal disorder. That day, as the doctor spoke, there was a part of me that wanted Camryn to be a "real" girl, in the same way Geppetto wanted Pinocchio to be a "real" boy.

I knew children with disabilities were held up not with strings, but with I.V. lines, braces and medication. They were also held up by their parents. But Cary and I were so unprepared. Who was going to hold *us* up?

Several years later, looking back at those feelings, I know what held us up—our friends, our family, our faith and networking with other parents. Sometimes Cary and I held each other up; other times, we simply "held on" because we had no choice.

Understanding helps, too—understanding that it's okay to have a child with a disability. By now, however, my wife and I have gone beyond "okay" to realize we have been truly blessed. It's ironic, but if people were judged by how loving they were, kids like Camryn would finish first in the human race.

Three-and-a-half-year-old twins Camryn (left) and McKenna enjoy "snow surfing" near their home in Issaquah, Washington.

Maybe we have something to learn from our "Pinocchios." Maybe they can teach us to be "real" parents. Knock on wood. **EP**

Gregory Burns lives in Issaquah, Washington, and works for Microsoft Corporation. His wife, Cary, is a full-time mom. They are the parents of four-year-old twin girls, Camryn and McKenna. Camryn has ring chromosome 14, a rare genetic disorder that causes seizures and developmental delays. There are fewer than seven known cases of the disorder in the U.S.

According to her dad, Camryn just loves people—especially Grandpa Richard Burns.

Gregory Burns dons a party hat to help daughters Camryn (left) and McKenna (right) celebrate their second birthday.

Fathers' Voices *is a regular feature of* EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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Frank Bernard Jr.

His comic strip finds humor in disability

Frank Bernard Jr., 28, is a cartoonist and the creator of "Funny as a Crutch," a comic strip series about the misadventures of Frankie, a young boy who walks with crutches, and Sharpton, his trusted porcupine companion. Bernard, who has spina bifida, attended the Massachusetts College of Art for two years. He created "Funny as a Crutch" in hopes that its readers would become more comfortable around people with disabilities. The comic strip currently appears weekly in a local Massachusetts newspaper, THE CHELSEA RECORD.

Bernard explains that he earns the bulk of his "cartooning income" doing caricatures at weddings, parties and other social functions. He also does occasional political cartoons for newspapers in the greater Boston area. In recent years, Bernard has become increasingly interested in animation. He would like to find work with an animation studio, maybe even move up to Disney one day. His short-term goal, however, is to have "Funny as a Crutch" syndicated. The following was adapted from an interview between Bernard and Michele San Filippo, an EXCEPTIONAL PARENT editorial intern.

I was born with spina bifida, meaning my spine was not fully developed. The doctor who delivered me didn't think I'd live past the age of two. My parents, Frank and Mary, really didn't believe that. They have always had a lot of faith in me.

Six hours after birth, I underwent the first of about 20 surgeries, this one to repair the opening in my spine. At six months, I had a shunt put into my head to drain spinal fluid that otherwise would go to my brain and kill me.

My parents have always been very loving, but they tend to be a bit overprotective. When I was growing up, they didn't give me much independence. They now drive me around to jobs doing caricatures at parties and weddings. Sometimes they want to give me rides when I don't need them. They always panic when I say, "No thanks. I'm taking the train."

Getting started

I used to hate art as a child, especially painting because it was messy. But cartooning looked like fun. At eight, I began doodling while watching cartoons on television. Bugs Bunny was the first character I learned to draw.

In fifth grade, I started drawing cartoons for the student newspaper. I invented characters like "Tippy, the Tiger" and "Harvey, the Dog Catcher." But I got my first real taste of cartooning "stardom" when I was in seventh grade at Our Lady of the Assumption School.

A friend of my mother's visited the school and saw me doodling. That afternoon, she took me down to the local newspaper, *The Chelsea Record*, and showed my work to the editor. The editor said to me, "You're in, kid." So I got my first gig when I was 12, and the paper published my work periodically from 1979 to 1981.

Trying to fit in

In 1981, I started high school. It was a very difficult experience because of social and physical obstacles. Chelsea High School had three floors and no elevators. People would sometimes help me carry my books, and I was given extra time between classes, but it still was very difficult.

The physical barriers at Chelsea High became such a distraction that in my junior year, I transferred to the high school in nearby Saugus, Massachusetts, because that school had only one floor. But although this move removed some physical barriers, it added new social barriers. I was no longer in my hometown; I suddenly had to adapt to a new school with unfamiliar teachers and students. Luckily, I made some friends who helped me along the way.

But I was never really comfortable at Saugus High, and my grades showed it. I should have graduated in 1985 but didn't have enough credits. I returned to Chelsea High for my senior year and graduated in 1986.

I had many friends who accepted me the way I was, but there still was some teasing. I tried to fit in. I tried to get people not to see my crutches. I would play baseball by dropping the crutches and throwing the ball around. I couldn't run, but I still tried to participate in athletics.

I would always explain my disability to friends immediately. Some were comfortable with the discussion; some weren't. I couldn't believe that there were

Four-year-old Frank (front) gives older brother Christopher, 6, a ride around the livingroom on the back of his toy moped.

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people who actually thought spina bifida was a disease you could catch. A lot of people still aren't comfortable around me, and it bothers me. That's one of the reasons I started doing "Funny as a Crutch."

"Funny as a Crutch"

During the summer of 1986, I was trying to come up with an idea for a comic strip when my mom suggested I do one about having a disability. My first reaction was, "Are you out of your mind? Who would want to read about a depressing subject like having a disability?"

Frank, celebrating his fifth birthday on April 30, 1972, shows he can blow out a candle from any position. At the time, he was in a chest-to-ankle cast following surgery to insert plates in his hips.

But then I thought, "It doesn't have to be depressing." I could do a comic strip about trying to find the humor in having a disability.

Before I even wrote the first strip, I tried to come up with a name for the series. That was when I recalled hearing on the television show "Happy Days" the expression "funny as a crutch," which meant "not funny at all." The phrase was perfect because it included both the words "funny" and "crutch."

Then I came up with the characters. The lead character's name would be Frankie, just like me. Frankie's best friend, Spike, was derived from friends of mine who were into punk rock. Spike had a mohawk hairdo. Frankie also had a pet dog named Bernard. After a few years, however, I decided to drop Spike and Bernard from the strip.

I wanted to give Frankie a new pet. I didn't want "Funny as a Crutch" to be just another of those boring boy-and-his-dog comic strips, so I started trying to think of an animal that had some type of disability. The first one that came to mind was a skunk, but there's already a cartoon skunk, "Pepe Le Pew." So I went with my second choice—a porcupine. Animals go out of their way to avoid porcupines because of their sharp quills, just like many able-bodied folks go out of their way to avoid people with disabilities. I named this new character "Sharpton," after the Reverend Al Sharpton.

Currently, the strip highlights the interaction between Frankie and Sharpton. Sharpton is Frankie's best friend.

continued on page 24

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continued from page 23

Having somebody to confide in all the time was something I didn't have growing up. In a way, Sharpton takes care of that for me.

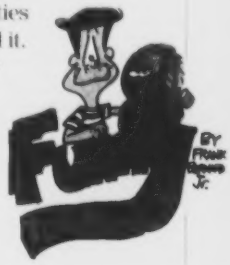
Achieving success

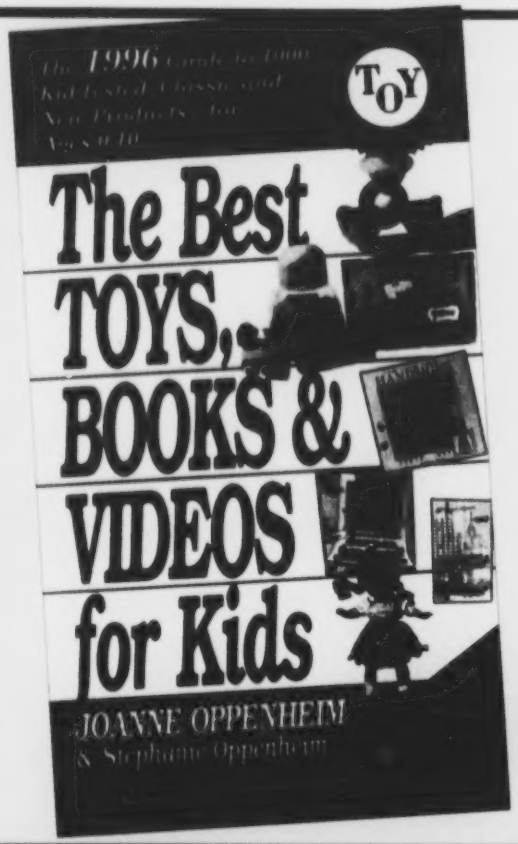
In 1987, I showed "Funny as a Crutch" to my old friends at *The Chelsea Record*, but they told me they couldn't use it. In 1988, *The Chelsea Weekly News* decided to use the strip, but that newspaper folded a few months later. But in 1991, my strip made some breakthroughs. First, I sent it to the Massachusetts Spina Bifida Association, and they published it in their newsletter. Then I sent it to *Insights*, a national publication for people with spina bifida, and they started using it. Finally, *Editorial Humor*, a national cartooning publication, did a full-page feature on the strip but stopped short of agreeing to publish it on a regular basis.

In October 1992, I called *The Chelsea Record*, determined to convince them to publish the strip regularly. It took a lot of persistence and nagging, but "Funny as a Crutch" debuted on October 21 of that year and has been there every Wednesday since.

The response has been very good. I've only gotten one complaint—the first year it was published, someone asked how I could make fun of people with disabilities. I answered, "I *have* a disability. Why would I want to ridicule myself?"

Doing the strip has been therapeutic. I never thought I'd be able to look back at painful experiences in a positive way, but with "Funny as a Crutch," I am able to do that. I hope other people with disabilities will be able to do the same when they read it. Actually though, I'm doing the strip mainly for the able-bodied. If they are enjoying it, I feel confident their attitudes are changing. Hopefully, people who read the strip will learn we're all basically the same. Everyone has disabilities of one type or another. **EP**





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USING ORDINARY TOYS FOR KIDS WITH SPECIAL NEEDS

Great Holiday Gifts

by Joanne & Stephanie Oppenheim

For more than 100 suggestions on how to adapt ordinary toys for kids with special needs, see the 1996 edition of **THE BEST TOYS, BOOKS & VIDEOS FOR KIDS** ***(HarperCollins, $12)*** by Joanne and Stephanie Oppenheim. The book is a comprehensive guide to more than 1000 classic and new products for children from infants to preteens, and is available through Exceptional Parent Library (800/535-1910).

As the holiday season approaches, a trip to toyland becomes a must. Before you go wandering down the aisles in search of the perfect gift, take a look at these kid-tested toys; they are entertaining, educational and easy to operate. These are ordinary toys that require little or no adaptation for children with disabilities. Most can be easily found in any toy store. Following the name of each toy, in parentheses, is its manufacturer, the recommended retail price and a customer service number that may be used for ordering or for more information on locating products. Following the description of some toys are suggested adaptations or activity tips.

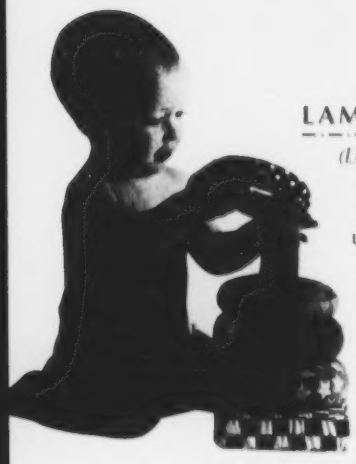
Most of these toys are versatile and will provide various kinds of play for children with different abilities. Although this article categorizes toys by age level, conventional age labels may be less meaningful for children with significant developmental delays.

INFANTS AND TODDLERS

FLOOR SPINNER

(Primetime Playthings, $13.95; 201/831-1400)

Infants and toddlers will find many sights and sounds to explore by turning and manipulating this intriguing floor toy. Each of the four cones has a distinctive activity—beads rattle, a beeper beeps, a mirror reflects and a tracking ball rolls through its track. Ideal for two-handed play and fun for crawling infants and toddlers to bat at and chase.



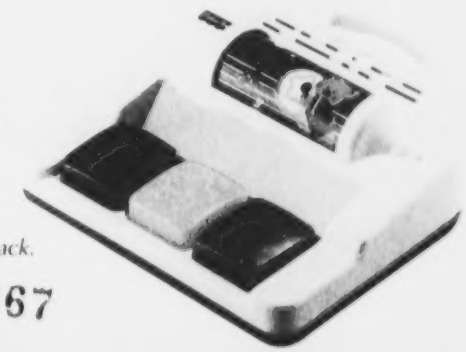
LAMAZE STACKING RINGS

(Learning Curve Toys, $19.99; 800/704-8697)

Here's a new look to the classic ring-and-post toy. These soft fabric rings are fun to listen to, with their built-in rattles and squeakers, and fun to look at, with their vivid patterns. Although they can be used for learning about size, there is no right or wrong—the rings will fit on the post in any order.

Adaptation idea: *Sew textures of terry, satin, corduroy or other fabrics to the rings for greater sensory feedback.*

Activity tip: *Play a "find-it" game. Spin two rings and have child find and grab the biggest ring or the blue ring or the smallest ring.*



LIGHTS AND SOUND PIANO

(Fisher-Price, $30; 800/432-5437)

This piano allows children to make a lot happen with a simple swipe of the hand. It has three big, light-up keys and a musical chime roller that plays a tune.

Adaptation idea: *Add glue textures or Braille dots to each key for tactile feedback.*

867

TANGIBALL

(Discovery, $9.98; 800/426-4777)

Kids can squeeze, sniff, roll, kick and enjoy this vanilla-scented, soft and squeaky four-and-a-half-inch vinyl ball. The surface is covered with small bumps for multi-sensory play. Fun to chase. Also great for early social games of rolling the ball back and forth.

AIRPLANE SWING*

(Little Tikes, $28; 800/321-0183)

A parent told us how useful this airplane swing, with its high back, has been for her three-year-old child, who needs extra support for sitting. Children practically wear this jolly airplane—it holds them all around and there is no place to slip through. Has an adjustable seat belt. Can accommodate children up to 50 pounds.

** EXCEPTIONAL PARENT featured this toy in "Using Ordinary Toys for Kids With Special Needs: Outdoor Fun" in June 1995. However, we inadvertently ran the wrong photo with the Airplane Swing description. We regret the error.*

BABY'S FIRST SILLY SOUNDS FARM

(Gund, $8; 908/248-1500)

Shake and squeeze these chubby, ball-shaped toys—a cow, chick, sheep and frog—to make them "moo," "peep," "baa" or "ribbit." They can be linked together by the velcro pads on their "arms." These cute critters are made of terry cloth and sold separately.

Activity tip: *With older tots, use these critters to animate a lively song of "Old MacDonald."*

DUPLO BABY

(Lego, $5.99–25; 203/763-3211)

These colorful stacking blocks with rounded corners are easier to fit together than other plastic blocks. Designed to stimulate the senses, the various box sets include mirrors, cars, people, animals that make rattle sounds and even a rock-and-spin block that twirls like a top. We suggest the Storage Bear set or the X-large Stack 'N' Learn set, which both come with an adapter for use with traditional Duplo blocks.

Activity tips: *Use words that describe each object's color, size or position as you play together. Put the toys away by playing a singing color game: To the tune of "Where is Thumbkin?" sing, "Where is red? Where is red? Here it is! Here it is!"*

More great holiday gifts on page 28

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PRESCHOOL AND EARLY SCHOOL-AGE

KETTRIKE JUMBO TRIKE

(Kettler, $109.90; 804/427-2400)

This sturdy red tricycle comes with a high-backed seat for secure sitting and a cargo hold in back. Detachable push bar allows parents to help as children learn to pedal.

Adaptation idea: *Add a seat belt, trunk support or foot harnesses to provide extra security. Two companies specializing in products that can be used to adapt riding toys—such as tricycles, scooters and rocking horses—are Sammons Preston, P.O. Box 5071, Bowlingbrook, IL 60440-5071, (800) 631-7277; and Flaghouse, 150 North MacQuesten Pkwy., Mt. Vernon, NY 10550, (800) 221-5185.*

MAGNETIC ALPHABET BOARD WITH BRAILLE LETTERS

(Playskool, $16.99; 800/752-9755)

This two-sided, magnetic alphabet board comes with 38 letters embossed with Braille symbols. One side has cut-out shapes, in alphabetical order, in which to fit letters. On the other side, children can use letters to make words. Storage space and carry handle are built-in. A 36-piece set of magnetic numerals and symbols embossed with Braille is also available ($3.99).

ROLL-A-ROUND PLAYGROUND

(Fisher-Price, $24.99; 800/432-5437)

Talk about making things happen! There's plenty of playful action built into this pretend setting. Three easy-to-grasp, roll-around critters fit into the working swing, slide, merry-go-round and peekaboo schoolhouse. A chunky, red lever activates the merry-go-round and provides lessons in cause and effect.

Activity tip: *Use the action of the toy to reinforce concepts of "round and round," "in and out," "up and down."*

ADVENTURE MOUNTAIN RACEWAY

(Little Tikes, $40; 800/321-0183)

This wonderful mountain has six fixed raceway courses—a loop-the-loop track, a twist-and-turn path that leads to a covered mine shaft, and two pairs of side-by-side courses that end with cars speeding off the mountain. This toy is excellent for promoting visual tracking and requires little dexterity to make cars start downhill. Comes with two cars. The mountaintop lifts to store 30 vehicles. Play with this toy on the floor not on a table, where the cars might fly off into children's faces.

Activity tips: *Mark cars with numbers and race two at a time to see which car is fastest. Or substitute colorful, giant beads or balls for cars. Or route toy train tracks through the tunnel.*

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MULTICULTURAL DOLLS & ADAPTIVE EQUIPMENT

(Constructive Playthings, $7.95–$39.95; 800/448-4115)

These 15" rag dolls have a younger and more cuddly look than vinyl dolls, and they are easier to bend to fit into a wheelchair. You can select a boy or a girl from four ethnic groups—Asian, Caucasian, Hispanic or African-American. Adaptive equipment includes a wheelchair, crutches, leg braces and eyeglasses.

FOLLOW-THE-LIGHTS KEYBOARD

(Mattel, $30; 800/524-8697)

Kids can play this Mickey Mouse keyboard in three modes: the automatic mode plays eight tunes; the keyboard mode allows kids to play tunes as they would on a piano; and the follow-the-lights mode guides kids through eight preprogrammed songs by "teaching" them to hit each key as it lights up.

Adaptation idea: *The lighted keyboard may be helpful to kids with visual disabilities, or Braille symbols can be added to large keys.*

I CAN SPELL! ALPHABET PUZZLE

(Tag Toys, $39; 800/488-4824)

Children working on letter- or word-recognition can explore these large wooden letters with both eyes and hands. Fit letters into puzzle board, or match them to letters on word picture cards to form familiar words.

Adaptation ideas: *Encourage child to trace letters with fingers. For children with difficulty grasping, add knobs to each letter. Also, make additional word cards with words of interest to your child. With a copying machine, enlarge the word cards so the letters on each are the same size as the wooden letters.*

Activity tips: *Play a game with letters: Put them in a bag and have child feel the letter and guess which it is before pulling it out. Play sound games with letters: Say, "I'm looking at the sound that starts the words 'pig,' 'pie,' 'Papa.' Can you find it?"*

MAISY GAME

(Briarpatch $20.99; 800/232-7427)

Spin the arrow, then find the object on the board that matches the color the arrow lands on. This game allows children to work on visual matching skills and develop a vocabulary for naming familiar objects. Features Lucy Cousin's storybook mouse, Maisy.

Adaptation idea: *To make the pieces more secure, place the playing board on a metal cookie sheet. Paste small magnets on back of playing pieces.*

Activity tips: *Play a sorting game by putting together all the striped pieces, all the red pieces. Play a riddle game by asking child to find "the round thing that rolls or bounces."*

These products were reviewed by the Oppenheim Toy Portfolio, an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes The Best Toys, Books & Videos For Kids *and also publishes a quarterly newsletter. Both publications include learning activity ideas and ways to adapt ordinary products for kids with special needs. To subscribe to the newsletter, send $12 to The Oppenheim Toy Portfolio, 40 East 9th, Suite 14m, New York, NY 10003.*

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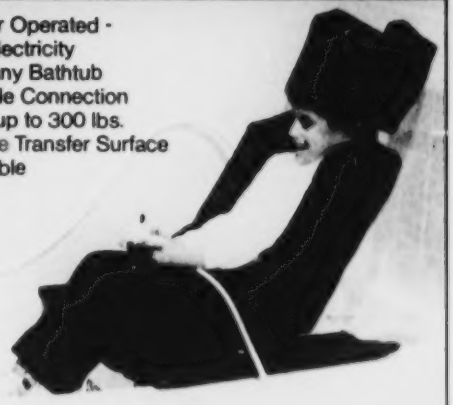

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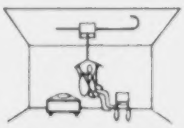

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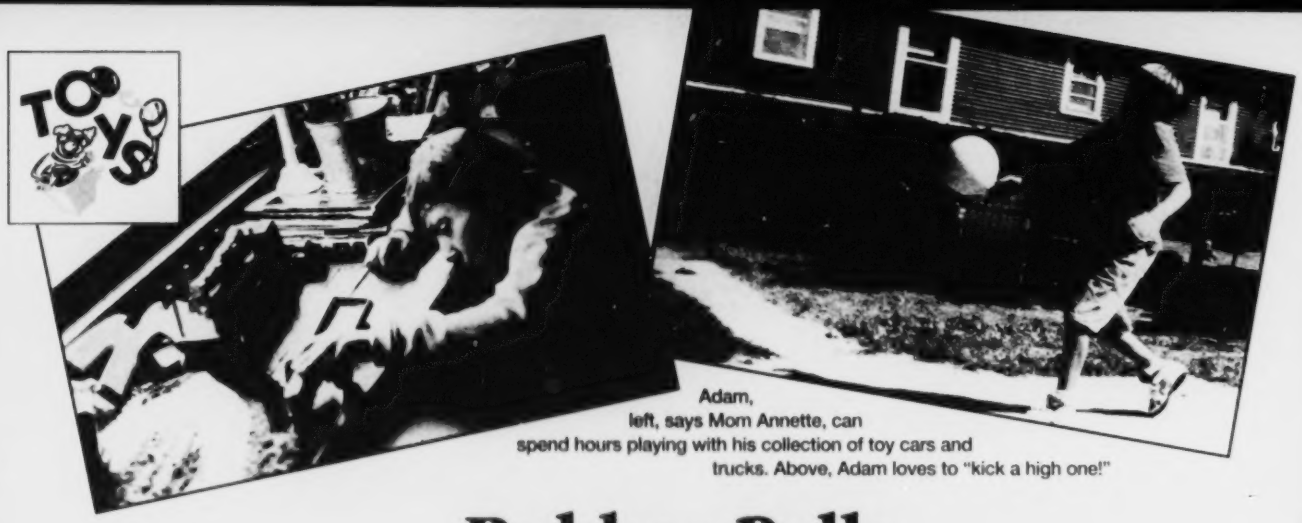

Adam, left, says Mom Annette, can spend hours playing with his collection of toy cars and trucks. Above, Adam loves to "kick a high one!"

Rubber Balls, Toy Cars and Art Supplies

For Adam, the simplest toys are the best

by Annette B. Heim

Adam's room looks like a toy store. There are several reasons for this. The first is that my 13-year-old son has an uncanny ability to find the toy department in just about any store, and he combines that ability with several successful tactics of persuasion.

The second reason has to do with a long-standing belief that I could make up for Adam's developmental delays by doing all the "right things." That included buying toys to stimulate and challenge his abilities—things like educational games, a computer and toys to aid in the development of fine- and gross-motor skills. Many of these games and toys have been helpful, and Adam has enjoyed their use. However, his favorite toys, and those most adaptable to his needs, are the most basic and least expensive—things like balls, toy cars and art supplies.

Adam likes balls because he can make them do whatever he wants. The movement of balls is predictable, and this gives Adam a sense of control over at least one object in his environment. In his words, he loves to "kick a high one!" Emotional security, practice in gross motor skills and social interaction—not bad for a simple two-dollar purchase!

Though he loves to kick and throw balls, Adam doesn't yet enjoy structured games requiring greater technique and knowledge. But as he matures, gains confidence and becomes interested in playing on a soccer or baseball team, his early ball play will form a good foundation for acquiring more advanced skills.

Adam's Hot Wheels and Matchbox cars reside in a large plastic box in the living room. They must be close at hand at all times! He has been collecting and playing with these cars for years. He can spend long periods of time "driving" cars along the window ledge, parking them, lining them up, placing them in groups and examining each one minutely. Small cars can be carried to church, to restaurants and in the car. Adam receives immense pleasure from playing with his cars, and we have the satisfaction of knowing that this activity contributes to gains in fine motor skills, eye-hand coordination, and sorting and matching skills.

A desk in our kitchen overflows with crayons, markers, paints, glues, rubber stamps, scissors, paper and Play-Doh. Adam loves to sit at the kitchen table, art supplies spread out around him, while he draws, cuts and pastes. Art is one of the most adaptable activities possible. Unlike a toy that can be used for only one activity, art materials are subject only to the interests and desires of the child using them.

Art allows children to experiment freely with colors, shapes, mediums and ideas. Because art does not depend on verbal language or great physical skill, it has become a powerful means of self-expression for Adam. He likes to draw pictures of his friends, his family, his dog and himself. As parents, we learn much about Adam and his feelings by observing his artwork.

Adam also uses art to make sense of the world around him. When he visits his grandparents' farm, he draws farm animals. When we moved to the Gulf coast and Adam first saw alligators in the bayous, he drew picture after picture of these new and exciting creatures.

Although art involves an individual process of creation, it often facilitates social interaction. Neighborhood children are attracted to our abundance of supplies, the artist's easel made by Adam's uncle and my willingness to let them "make a mess." Everyone benefits.

What do balls, toy cars and crayons have in common? They stimulate mind, body and spirit; they adapt to the abilities of the growing child; and they are so much fun that they will *never* gather dust on the toy shelf. **EP**

Annette B. Heim lives in Mobile, Alabama, with her husband, Bret, and son, Adam, 13. Annette is a librarian and musician. Adam has partial trisomy four, a chromosomal disorder. This year, for the first time, Adam is being homeschooled.

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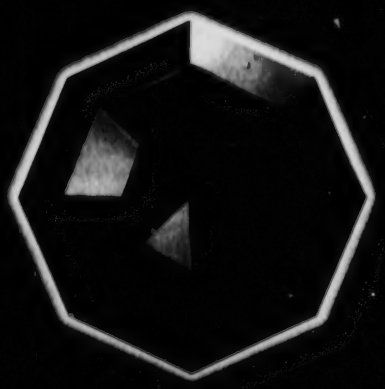

"49 MILLION ON"

AMERICA'S DISABILITY CHANNEL

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Ramps and Lifts

Meeting the need for access

A vertical platform lift makes the entrance to this house accessible. (Photo courtesy of Mac's Lift Gate, Long Beach, CA)

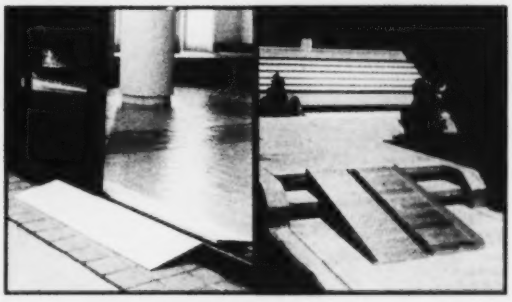
Even in areas with relatively flat terrain, access to many community activities—housing, education, health care, transportation and employment—requires moving from one level to another. As a result, despite gradually-changing building and recreational facility designs, children and young adults who have difficulty going up or down stairs can be restricted from participating in day-to-day activities.

Ramps or lifts can make it possible for a child or young adult with physical disabilities to have independent access to his or her home.* In recent years, many access options have evolved. Parents can gather information about these options to determine which one(s) will best meet their child's need for access and their family's budget and space requirements.

In this building, the second floor is as easy to get to as the first. (Photo courtesy of The National Wheel-O-Vator Company, Roanoke, IL)

Ramps

Although sidewalks and driveways are often level, entrances to most homes include stairs. Ramps or graded pathways can make such entrances accessible. These ramps and pathways require the proper degree of slope; a ramp must be 12 inches long for each inch it rises. A steeper ramp is much more difficult to use, and more dangerous. Although a gradual straight ramp is the easiest to use, many homes do not have sufficient ground space to accommodate a straight ramp. "Switch-back" ramps—ramps that make turns—take up less space and may also be more aesthetically pleasing. It is important, however, to have adequate turning space at each point where the switch-back ramp changes direction.



Portable ramps are perfect for traveling—easy to transport and store. (Photos courtesy of Homecare Products, Inc., Kent, WA)

Ramps can be made of wood, metal, concrete or asphalt. Whatever the surface material, the ramp must provide safe access, regardless of weather conditions. This means all surfaces must be slip-resistant, even when wet. Building a roof over a ramp is recommended; a covered ramp will also be easier to maintain.

Other necessary safety features include curbs to prevent a wheelchair from rolling over the edge and handrails to provide security for a child in a wheelchair or one who needs assistance walking. Handrails need to be continuous, easy-to-grasp and slip-resistant. Metal rails are durable, but they ideally should have an insulated coating as metal can become hot in the summer and extremely cold in the winter.

Lifts

Ramps are a good solution to access needs when there is adequate space. However, if space is too tight for a ramp, a lift may be the solution. There are three main types of lifts: platform lifts, stairway lifts and elevators.

The first type, the platform lift, allows a child who must remain in his or her wheelchair to go up and down stairs. Vertical platform lifts, which travel straight up and down, can be installed inside or outside, and can be open or enclosed. These lifts usually travel vertically up to 8 feet; lifts that travel as far as 12 feet are also available. The lift must be big enough for a large wheelchair (30" x 48"), and all surfaces on the lift—including the approaches to it on each level—must be slip-resistant. At the top and the bottom of the lift route, you'll need enough space to open the swinging gate and allow the child to get on and off easily. The person riding the lift must be able to reach and use the controls. For younger children, adults may need to control the lift with a locking system. Finally, the lift should have a call button to summon help if needed.

A platform lift can also be installed *on* a stairway. These platforms, called "stairway inclined lifts," are useful if the distance between floors or between stairway landings is too steep for a ramp. Some stairway inclined lifts fold up, to open up the stairway for people who will not be using the lift. Certain lifts of this type can even be installed on curving stairways.

Residential elevators are another solution for a child who must remain in his or her wheelchair. However, because they require enclosed shafts and must be installed very carefully so as not to interfere with critical structural elements or roofing systems, such elevators are

A stairway inclined lift is installed directly onto the stairway. (Photo courtesy of Econol Elevator Lift Corp., Cedar Falls, IA)

continued on page 36

Ramps and lifts are also available for getting in and out of vehicles, swimming pools, beds and bathtubs, but these products are not described in this article.

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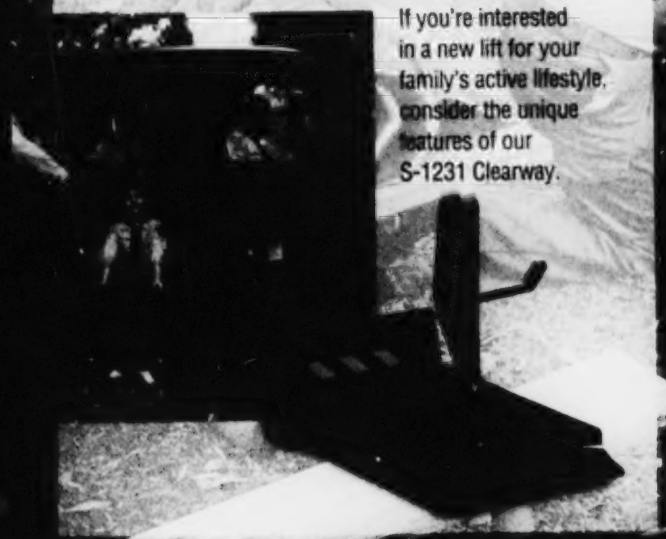

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Circle #249

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more expensive and less practical than some type of platform lift.

A platform lift or elevator may not be necessary in all cases. When a child with a disability is able to transfer from his or her wheelchair, sit comfortably and safely, and walk short distances, the child can use a stairway lift with a seat, sometimes called a "seat lift."

Vertical platform lifts allow independence both at home and in school. (Photos courtesy of Access Industries, Inc., Grandview, MO)

The manufacturer or manufacturer's representative usually installs lifts, but may not be able to complete the related electrical work. Other necessary work may include structural work on the concrete "pad" at the bottom of the lift and carpentry if the lift is enclosed. As with any adaptive equipment, a lift needs testing and service, and parents or teachers who will be operating the lift may need training. Finally, the lift's design and construction must meet local building and fire codes. **EP**

The material in this article has been adapted with permission from the ADA Cost Catalog for Access Modifications, a publication of the Adaptive Environments Center, Boston, MA, in collaboration with R.S. Means, and with the support of the National Institute on Disability and Rehabilitation Research (LRP Publications, Dept. 450, P.O. Box 980, Horsham, PA 19044-0980; 800/341-7874, ext. 347; $39.50 incl. shipping), and from A Consumer's Guide to Home Adaptation (available from Exceptional Parent Library, 800/535-1910).

Industry pricing guides are another important resource for anyone considering ramp construction or the installation of a lift. These guides provide detailed lists of the costs involved, including specific materials, labor and contractors' overhead expenses. Guides are available in some libraries or can be purchased from R.S. Means (P.O. Box 800, Kingston, MA 02364-0800; 800/448-8182 or 617/585-7880; $19.95–80.00).

Construction and installation costs

Providing home access through ramps and/or lifts is one more financial burden for the families of children with physical disabilities. Costs are usually tax-deductible as a medical expense, which can help families who itemize deductions, and service organizations or certain government agencies can sometimes help families pay for ramps and lifts. Usually, however, families bear most of the costs themselves. While the do-it-yourself method can help cut costs, it is feasible only for ramps—the installation work necessary for lifts and elevators requires the skill of a trained manufacturer's representative.

Even for ramps, the do-it-yourself method has its limitations. Ramp construction or installation usually requires a skilled contractor who has had experience with adaptive construction. Even highly skilled "non-professionals" may need to consult with experienced contractors or architects.

A range of guides to contractor selection is available to consumers. When considering various contractors, it is useful to get the names of previous customers who have contracted for similar projects, to ask them questions about quality, reliability and cost. Whenever possible, take a look at the work that was done for these customers and have your child go for a "test ride" on their ramp or lift.

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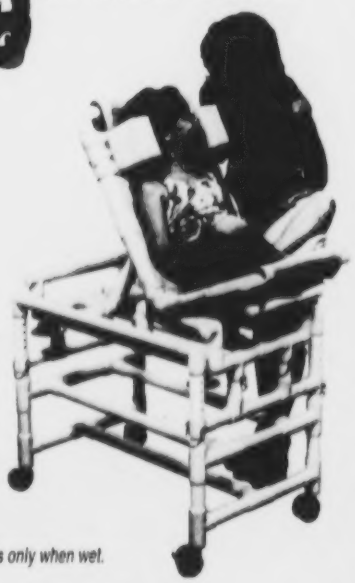

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Beyond Labels

How to use information about specific diagnoses

by Karen Levine

Bill wanted to help his 10-year-old daughter, Kate, fulfill her dream of learning to ice skate. Bill knew this would be a challenging task because Kate, like other children with Williams syndrome, had coordination difficulties and problems with "motor planning"—the ability to get one's body to move in the complex ways necessary for activities such as skating. On the other hand, Bill knew that a strong sense of rhythm and love of music were characteristics also associated with Williams syndrome. This gave him an idea about how to approach the task. Bill and Kate hit the ice rink armed with a tape recorder and cassettes of Kate's favorite music. Using the rhythm of the music, Bill was able to help Kate learn to perform the smooth movement sequences the activity required. Those "skating lessons" with Dad paid off. Kate, now 16, is an enthusiastic recreational skater who regularly participates in a sport she can enjoy for many years to come.

Some people say, "I don't want to know about the disability. I just treat all children as individuals." But information about a child's specific diagnosis does not have to limit one's expectations for a child. Rather, as Kate's story illustrates, this type of information can be used to guide approaches that will extend the vision of what is possible. Here are some important uses of information related to specific disabilities:

• **"Normalization" of unusual behavior:** Information about specific disabilities allows teachers and parents to gain a fuller understanding of unusual or confusing behaviors or developmental patterns. Behavior that might be unusual or disturbing in a typical child may be expected, even typical, for a child with a specific syndrome.

This understanding can prevent misinterpretation and unnecessary searching for the "cause" of confusing behaviors. One example is the common food-seeking behavior of many children with Prader-Willi syndrome (PWS). If another child were to seek food with the same degree of intensity, one might suspect significant emotional problems, poor self-control or even an undiagnosed metabolic disorder. But knowing that this behavior is normal for children with PWS prevents unnecessary concern; it also prevents the placement of blame on the child or family. Parents and teachers who are knowledgeable about the impact of PWS realize they cannot simply "teach" the child not to seek food. Because food-seeking is a biologically-driven tendency in children with PWS, usual behavioral modification techniques just won't work. Knowing this, parents and teachers can move on to exploring strategies for adjusting the environment so that the child's food-seeking tendency causes as few problems as possible. This might mean storing food where it is out of sight or serving food in portions, rather than buffet-style.

Just as important, this understanding of behaviors or difficulties as "normal" effects of a specific disability can be extremely reassuring for the child as well. For example, a teenager with Down syndrome who feels frustrated with her "messy" handwriting may find it reassuring when her teacher explains that most children with Down syndrome have low muscle tone, making handwriting more difficult. This understanding allows the child to correctly identify the source of the difficulty as "out there"—part of the impact of the syndrome—rather than as a personal weakness or shortcoming.

Siblings and classmates can also benefit from knowing that some challenging behaviors are due, in part, to "the syndrome." For example, the sister of a boy with autism may wonder why her brother does not greet her verbally when he comes home from school. She may be reassured to know that this is "normal" for a child with autism.

• **Ability to use known intervention or teaching strategies:** Information about a diagnosis allows teachers and parents to take advantage of tried-and-true intervention or teaching methods, without having to "reinvent the wheel." For example, although children with Rett syndrome can be challenging to engage, parents who know that music is an intense love for most children with the syndrome have a head start when looking for interesting activities. Similarly, a teacher attempting to design a lesson to hold the interest of a child with Rett syndrome may also take advantage of the child's love of music.

• **Availability of support networks:** A diagnosis provides access to networks of other parents and professionals working with children who have similar strengths and challenges. Most disabilities with a diagnostic label have regional and national family/professional organizations; many publish newsletters and hold conferences. *[EDITOR'S NOTE: The EXCEPTIONAL PARENT 1995 RESOURCE GUIDE (January 1995) lists nearly 400 resource groups for specific disabilities. An updated RESOURCE GUIDE will be published in January 1996.]*

• **Increased appreciation of a child's strengths:** Many behavioral tendencies associated with the diagnosis of a specific developmental disability may be viewed as positive characteristics by a child's peers, teachers and family. For example, the social disinhibition and unrestrained emotions often associated with Williams syndrome may add up to a youngster who is an enthusiastic, outgoing and charismatic member of his family and classroom.

Kerry Ann Bouffard celebrates her 13th birthday with her parents Judith and Richard. Kerry, who lives in Groveland, Massachusetts, has autism. (Photo courtesy of the Autism Support Center, Danvers, MA)

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What about the child without a specific diagnosis?

Many children with developmental disabilities do not have a specific diagnostic label. It is common for parents and teachers to believe that the behaviors such a child exhibits—everything from level of arousal to tantrums—stem from the child's unique personality and experiences. However, even in the absence of a diagnostic label, many behaviors may be associated with biological aspects of the child's disability. For that reason, the strategies and interventions described in this article may be useful for children who do not have specific diagnoses, but whose behaviors and learning profiles are similar to those associated with known syndromes and disabilities.

To better understand and intervene, it will be helpful to ask some basic questions about a child's behavior: How long has the child exhibited this specific behavior or "behavioral style?" Is it consistent across situations? And does the child have any medical problems? For example, a child who seems to have little energy may be feeling ill, may be depressed, may have some sort of metabolic problem or may have a low level of arousal related to his or her undiagnosed disability.

Can there be any harm in "labeling" children?

It is important to avoid several potential abuses of diagnostic labels. First, a label should not serve to limit the goals or expectations for a child. In every diagnostic category there are some individuals who exceed all expectations, and whose disabilities have only the mildest of impacts. And *all* behavior is susceptible to environmental influence.

Second, it is important to view a child's diagnosis as just one of many factors contributing to who a child is. Not everything unique about the child is related to his or her disability. All children, with or without disabilities, are influenced by their families, their teachers, their peers, their life experiences and their biological and genetic makeup.

Children with Williams syndrome are often noted for their enthusiastic, outgoing personalities. (Photo courtesy of Williams Syndrome Association)

Third, it is important that information about a diagnosis not be used as a license for a child to engage in unacceptable behavior. For example, a child with autism or Prader-Willi syndrome may be more likely than other children to have tantrums when frustrated. In spite of this disability-related tendency, children should be expected to try to control their behavior. Furthermore, parents and teachers can deal with these tantrums as they would with the tantrums of a child who does not have a disability. This may mean, for example, removing the child to a separate room as soon as he or she begins to scream. Certain ground rules need to be applied universally, regardless of a child's disability.

Finally, it is important to remember that diagnostic labels have the potential to be stigmatizing. This recognition has led to many recent changes in the terminology used to describe disabilities. "People-first" language—for example, saying, "a child with Down syndrome," rather than "a Down syndrome child"—represents an attempt to ensure that the child comes before the label. Diagnostic labels that are especially stigmatizing, such as "mental retardation," are perhaps best used only for specific purposes, such as when parents and teachers are looking up information, but not in everyday conversation about the child.

Can behaviors that are known to be part of a syndrome be modified through the same intervention approaches that help other children with the same behaviors?

Most behaviors associated with syndromes can be modified to some extent, although the behavior may be more difficult to modify than the same behavior in other children. Here are some steps parents and teachers can take when considering attempts to modify behaviors associated with specific disabilities:

• *Consider whether the behavior has a function or purpose for the child.* This process, sometimes called "functional analysis," can help parents and teachers determine whether the behavior in question really *needs* to be modified. At best, some "unusual" behaviors associated with a developmental disability may serve an important function. At the least, the behavior may be harmless. For example, the hand-flapping of a child with autism may help the child express excitement in a way that allows others to respond. This behavior may not need to be altered, at least not until the child learns other ways to express excitement.

Behaviors that are highly resistant to change often serve a function—as difficult as it is to know exactly what that function might be. For example, some people theorize that the gaze aversion often present in children with fragile X syndrome when they are speaking, may be a strategy they use to better concentrate on their words without being distracted by the visual stimulation of a face.

Even if the behavior seems to have a function for the child, it may be possible to teach other behaviors that have the same function but interfere less with everyday life. For example, a child with autism who screams when the room gets too noisy may be taught to put on headphones instead when excess noise occurs.

• *Find ways to reduce stress.* When under stress, most people have more difficulty controlling what might be considered "biologically-driven" behaviors. In stressful circumstances, for example, people may eat more, bite their nails or have trouble paying attention. Finding ways to reduce a child's stress and maximize his or her happiness and success can lead to a reduction in many challenging behaviors.

• *Establish specific environmental adaptations.* Some behaviors associated with a developmental disability can be modified by changes in the environment. For example, the food-seeking behavior of a child with Prader-Willi syndrome can be reduced if food is stored out of sight. And a rocking chair in

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the classroom may provide a socially acceptable outlet for a child with Williams syndrome who has a tendency to "rock" his or her body. Consultation with a behavioral psychologist is often helpful.

• *Try techniques of positive behavioral management.* This means making sure the challenging behaviors do not receive "rewarding" responses, while other, more desired behaviors do.

Lindsay Williams and David Gammon enjoy playing Nintendo. Lindsay and David live in a specialized group home for individuals with Prader-Willi syndrome. (Photo courtesy of Keystone City Residence, Scranton, PA)

Sometimes parents or teachers are surprised to find they have been inadvertently rewarding a behavior they are trying to modify. For example, a child with autism may flap his hands when he gets excited. In an attempt to stop this behavior, whenever the child flaps his hands, a parent or teacher approaches the child and holds his arms down. Suppose, however, that the child enjoys this attention and closeness; how long before the child learns that hand-flapping leads to hugs? As a result, the child's hand-flapping behavior may actually increase—the opposite result of that intended by the adults in his environment!

• *Medications may be useful.* Many biologically-regulated behaviors can be modified through the use of medications, particularly when combined with changes in the child's environment. It is important to respect the legitimate philosophical stance of families who do not wish to use medications with their child. But increasingly, psychotropic medications are being used to influence many of the behavioral challenges associated with specific developmental disabilities.

For example, the skin-picking and other perseverative behaviors associated with Prader-Willi syndrome are often very responsive to a combination of stress-reducing environmental modifications and treatment with medications such as Prozac. The hyperactivity and distractibility often seen in children with Williams syndrome, and in some children with Down syndrome, is usually helped substantially by reducing environmental stimulation, increasing structure, and sometimes by the use of a stimulant medication such as Ritalin. The extreme anxiety of many children with autism may also respond to medication, along with environmental changes such as predictable schedules.

Medication will not help every child. Some children respond to certain medications very successfully; others may show only a mild response or none at all. For some children, a medication may even have the opposite effect of that intended. A child using any medication, especially a relatively new psychotropic medication such as Prozac, must be closely monitored by his or her medical team. At least one member of that team should be an expert in the use of

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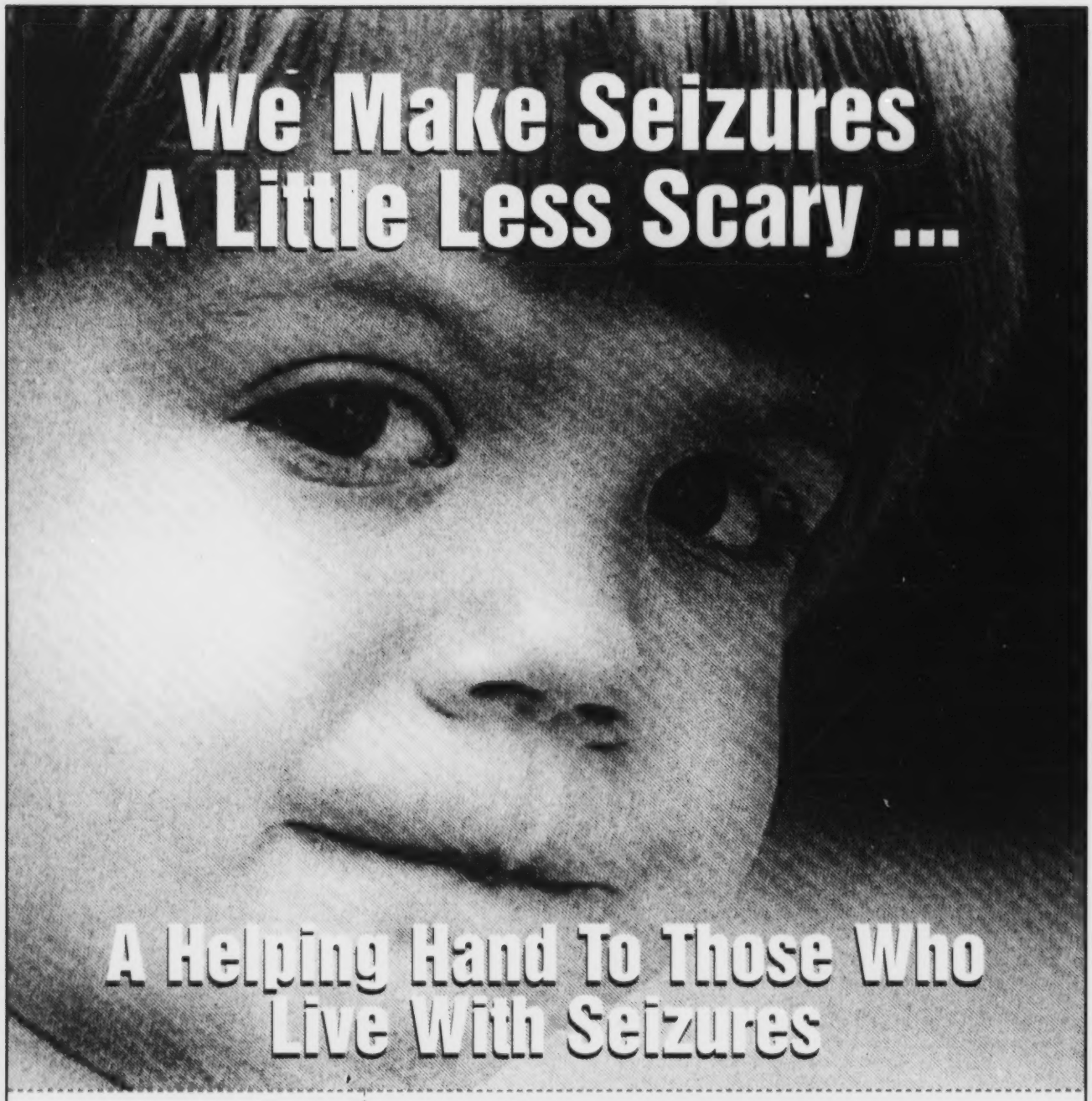

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Developmental Syndromes: Impact on Learning and Behavior

This table provides information regarding behavioral and learning characteristics that tend to be associated with four specific diagnoses—Williams syndrome, Prader-Willi syndrome, Down syndrome and autism.

The table reflects a model for thinking about children's strengths and challenges, but it is important to remember that it is based primarily on the observations of professionals and parents, rather than on the results of conclusive research.

In the table, plus symbols (+, ++, +++) indicate increases in a specific behavioral or learning characteristic in relationship to a particular diagnosis. For example, "+" indicates a slight increase in the level of a specific characteristic in relation to a particular diagnosis; "++" indicates a significant increase; and "+++" indicates a very significant increase. Minus symbols (–, – –, – – –) indicate decreases. "N.A." indicates that there is no particular relationship between the behavioral or learning characteristic and the specific diagnosis. For example, the table indicates that children with Williams syndrome have very high levels of "sociability," while children with autism have very low levels of this characteristic. The table also indicates that "sociability" is not a characteristic that seems to be affected one way or another by a diagnosis of Prader-Willi syndrome or Down syndrome.

Behavioral/Learning Characteristics	Diagnosis			
	Williams syndrome	Prader-Willi syndrome	Down syndrome	Autism
Sociability	+ + +	N.A.	N.A.	– – –
Arousal	+ + +	– – –	–	+
Anxiety	+ +	N.A.	N.A.	+ +
Attention span	– – –	N.A.	N.A.	+/–*
Perseveration	+	+ +	N.A.	+ +
Appetite	–	+ + +	+	–
Depression	N.A.	+	N.A.	?
Spatial analysis	– – –	N.A.	N.A.	+ + +
Expressive vocabulary	+ +	+	–	+
Pragmatic language	+ + +	+	+ +	– – –
Face analysis/memory	+ + +	N.A.	N.A.	– – –
Hyperacusis	+ + +	N.A.	N.A.	+ +
Touch sensitivity	+ +	N.A.	N.A.	+ +
Fine motor ability	– – –	N.A.	–	+
Gross motor ability	– – –	– – –	–	+

** Some children with autism appear to have a very short attention span. Many others seem able to attend for very long periods to some activities, while attending only briefly to others.*

DESCRIPTIONS OF SYNDROMES

Williams syndrome (WS) is a non-inherited developmental disability caused by a genetic mutation. WS usually results in a variety of developmental differences, often including learning problems, with strengths in language and weaknesses in math and handwriting. Children with WS often have high levels of sociability, musical talent and a short attention span. WS results in a variety of physical differences, including a unique facial appearance, shorter height and an increased risk of heart problems. WS occurs in approximetely one in 20,000 individuals.

Prader-Willi syndrome (PWS) is a non-inherited developmental disability caused by a genetic mutation. PWS usually results in a variety of developmental differences, usually including learning problems, with strengths in long-term memory and reading, and weaknesses in short-term auditory memory. Individuals with PWS are usually social and nurturing. Physical characteristics usually include a unique facial appearance, shorter stature, heightened appetite and difficulty controlling behavior when upset. PWS occurs in approximately one in 20,000 individuals.

Down syndrome (DS) is a non-inherited developmental disability caused by a genetic mutation. DS results in a variety of developmental differences including learning problems (usually mental retardation) and better receptive than expressive language. Physical characteristics include a unique facial appearance, short stature, low muscle tone and an increased risk of heart problems. DS occurs in approximately one in 500 individuals.

Autism is a behaviorally-diagnosed developmental disability, identified by difficulty in sustaining social interaction. Children with autism show a diminished use of verbal language and nonverbal communication, including eye contact and gestures. Autism occurs in approximately one in 2,500 individuals.

Sociability: Children who have high levels of sociability often prefer to be interacting with others and may have trouble "tuning out" people to attend to work. Children with low levels of sociability may be difficult to engage or play with, and may make little eye contact.

Arousal: Children with a very high level of arousal may be easily upset, irritable or hypervigilant (easily distracted by the smallest sights and sounds around them). Adults may describe them as "high-strung." Children with a very low level of arousal may appear sleepy much of the time, may be slow to respond to external stimulation and may appear sedentary. They may fall asleep easily, even during normal waking hours, if there is a lack of external stimulation.

Anxiety: Children with a high level of anxiety may seem perpetually worried, may become distressed or agitated very easily, and may become especially upset at the anticipation of stressful events. Children with lower levels of anxiety will be more relaxed and will tolerate changes relatively easily.

Attention span: Some children are able to sustain and shift attention as needed for a variety of activities, while others have a very short attention span and trouble staying with activities, even activities they seem to enjoy. Children with short attention spans are often quite easily distracted by other events occurring in the same room.

Perseveration: Children with high levels of perseveration tend to "get stuck on" favorite activities or topics. Children who perseverate may ask the same question over and over, even though they know the answer, or may engage repetitive toy play. Most people perseverate more when under stress.

Appetite: Appetite can be influenced by emotional factors (for example, some people eat more—or less—when depressed), but, to some extent, appetite is also biologically regulated. Some individuals are biologically driven to consume more calories than they can burn up.

Spatial analysis: Spatial analysis means making sense of visual information in which the spatial orientation (for example, left versus right) is crucial. Spatial analysis is involved in such diverse tasks as learning to recognize letters of the alphabet, organizing written work, drawing pictures, assembling puzzles, tying shoes and finding one's way around. Children with better spatial analysis skills are more likely to experience success with these tasks.

Face analysis/memory: To some extent, the ability to remember faces is biologically programmed. Some people are much better naturally at this task than others.

Hyperacusis: This refers to a heightened sensitivity to certain types of sounds, and difficulty "tuning out" background noises. A child with hyperacusis may find certain sounds—such the sounds of vacuum cleaners or ceiling fans—unpleasant. Such children may be disturbed by the humming of an electric clock or water in the pipes, sounds other people may not even notice.

Touch sensitivity: Children with high levels of touch sensitivity may find certain kinds of seemingly mild touch sensations very unpleasant. To such a child, a tag in the neckline of a shirt may feel like sandpaper. The child may object strenuously to having his hair brushed or cut. He may refuse to wear a hat, or find certain food textures intolerable.

Fine motor ability: This refers to hand coordination and strength. Children with high levels of fine motor ability are more likely to experience success with such tasks as writing, drawing, dressing, tying shoes and manipulating small items like blocks or coins.

Gross motor ability: This refers to coordination and strength of the legs, arms and body. Physical activities that use large muscles—activities like walking, running or riding a bike—involve a great deal of gross motor ability.

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Kaitlin Aubrey Charlton (front) enjoys an afternoon romp with her buddies, Danielle and Allison Regester. Kaitlin, who has Down syndrome, lives in Bel Air, Maryland. (Photo courtesy of the National Down Syndrome Society)

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the medication, and should make other team members and parents aware of possible undesired side effects. It is important to remember that some medications which are helpful at certain doses, can become dangerous (toxic or poisonous) at higher doses.

• *Try to help the child make the most of his or her abilities.* Some syndrome-related characteristics, such as the low muscle tone associated with Down syndrome, are less modifiable. However, occupational and physical therapies, along with environmental adaptations, can support a child's ability to use his or her abilities effectively.

Learning what makes a child "tick"

Information about specific disabilities helps parents and teachers understand more about what makes an individual child "tick." This allows these adults to more effectively help the child draw on his or her strengths while overcoming or working around challenges. Parents, teachers, friends, classmates and siblings need to be able to learn about and feel comfortable with behaviors that initially may seem confusing or upsetting. This understanding enables others to more deeply appreciate the child with a disability. And knowledge of the unique strengths and challenges related to a specific diagnosis can be equally invaluable for children with disabilities themselves. **EP**

Karen Levine, Ph.D., is director of psychology at the University Affiliated Program, Institute for Community Inclusion, Children's Hospital, Boston, Massachusetts. She is also an instructor at Harvard Medical School. Dr. Levine specializes in psychological consultation for children with autism, Williams syndrome and other developmental disabilities, and their families.

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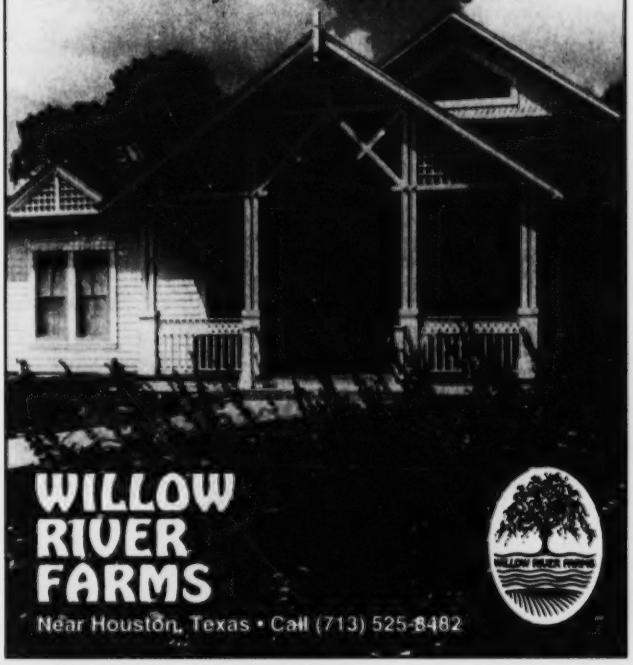

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Fighting For Our Lives

by Bob Williams

When many of us joined President Clinton's administration, we did so with a sense of hope and renewed commitment to bettering the lives of children and families. We had reason to be upbeat and optimistic, especially regarding the federal policy outlook for Americans with significant disabilities and their families.

Sadly though, these past 12 months have made a terrible difference. We all know why this has happened, so I will not spend time reviewing the obvious. But collectively, Americans with disabilities and our families are now facing the fight of a lifetime.

A personal and historical context

I want to put this in a personal, as well as historical context. Like increasing numbers of individuals with significant disabilities, I have beaten the odds society stacks up against us—prejudice, stereotypes and continuing discrimination. I owe my success, first and foremost, to my parents, who refused to accept society's low expectations for the youngest of their five children. Instead, they helped me to set and achieve high expectations.

Bob Williams is Commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services. Williams has cerebral palsy and uses augmentative communication.

This article was adapted from a speech Williams gave at the 1995 National Collaborative Academy on Mental Retardation, sponsored by the President's Committee on Mental Retardation.

And, like many others with severe disabilities, I owe at least part of my success to the luck of having been born at an extremely fortunate time in our nation's history. This is critical for today's parents to understand, because some people in our country seem intent on turning back the clock.

Many of us remember a much different time. In the early 1960s, for example, children with cerebral palsy who drooled, as well as children considered to be mentally retarded, were legally barred from attending most public schools in my home state of Connecticut.

Fortunately, those laws changed. By the mid-sixties when I started school, things had improved. Even so, my first classroom was in a church, not because my parents were particularly religious, but because this was the only place in town that would have us.

A few years later, I asked the special education director of my town why I couldn't go to the same school as my brothers and sisters. His reply was as straightforward as my question; he told me I couldn't go to regular classes because I didn't speak clearly enough.

I never did develop clear speech. But something else changed. As simple technology like electric typewriters, computers and communication devices became more available, expectations increased. Parents became bolder and more organized. As a result, state laws began to change.

Soon, access to a regular school classroom was no longer seen as a privilege but as our right. By 1975, federal law was on the side of millions of students with disabilities who were intent on getting a high-quality education in the maistream.

A few years later when I graduated from high school and wanted to go on to college, federal law was on my side again—this time in the form of the Rehabilitation Act of 1973. When others expected me to go quietly into a sheltered workshop for the rest of my life, my parents and I had other ideas. And we knew the Rehabilitation Act was one of our strongest tools for pursuing the future we envisioned.

On July 26, 1990, a day of historic promise and opportunity, the Americans with Disabilities Act (ADA) was signed into law. And thanks to President Clinton's effective enforcement of the ADA, we have continued to make significant progress in opening previously-closed doors.

Today, however, we are at a fundamental turning point with respect to the kind of future we can expect for ourselves and the kind of future all of our young people can expect to inherit. "Inclusion-bashing" is becoming more and more popular. Many people are quick to blame inclusion for whatever ails our schools and country; it is placing the blame on those of us who act, think or express themselves differently.

"Forces of derisiveness and division"

As President Clinton told a group of us who met with him to mark the fifth anniversary of the ADA, the forces of derisiveness and division are all around us, threatening to undermine the civil rights of all Americans, including children and adults with disabilities.

- **IDEA:** We are facing real challenges to reauthorizing the Individuals with Disabilities Education Act (IDEA). This law enabled nearly two million of us to get a quality public education. Now there are those who want to take this opportunity away.
- **ADA:** The ADA is also under attack. President Clinton has stated that he will veto any attempt to repeal the law. But he has warned that there will be more subtle, but still potentially damaging attacks aimed at cutting ADA technical assistance and enforcement efforts.
- **SSI:** Similarly, SSI payments to children with disabilities are under intense scrutiny. Under a House-approved plan, approximately 177,000 children with disabilities would lose all SSI benefits and Medicaid. An additional 613,000 kids would lose SSI benefits while retaining Medicaid eligibility.

While there is no question that the childhood SSI program is in need of restructuring, this can be done without wrecking havoc on the lives of these kids

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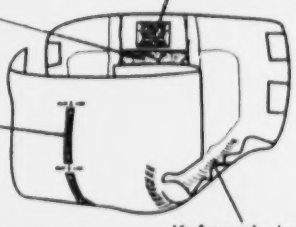

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and their families. The childhood SSI program has been a big factor in the reduction of admissions of children with mental retardation to state institutions. Today there are still some 4,000 such youngsters in these facilities—4,000 too many. But 30 years ago, there were 98,000 kids in these places. Do we really want to return to those times?

• **Medicaid:** If you've been thinking this is just a lot of federal gobbledy-gook that doesn't affect you or your family, think again. Chances are that most Americans with significant disabilities will be affected by proposed cuts to the Medicaid program.

Everyone agrees that Medicaid is out of control. The program now costs 88 billion dollars annually; within five years, that cost is expected to reach 150 billion. This is clearly unacceptable. But despite its many flaws, it is important to remember that Medicaid is the major source of day-to-day survival for millions of individuals with significant disabilities. It pays for personal assistance, assistive technology and other support services. Without it, hundreds of thousands of our sons, daughters, brothers and sisters will once again end up lying in their own excrement.

SOME PEOPLE IN OUR COUNTRY SEEM INTENT ON TURNING BACK THE CLOCK.

President Clinton has proposed several ways to reform the Medicaid program. His suggested remedies include truly comprehensive national health reform, grants to help states expand access to consumer-driven personal assistance and, most importantly, the elimination of the federal deficit—not in seven years—but over a 10-year cycle so needed cuts can be made more gradually, at far less human expense and with much more forethought. Tragically, the Republican leadership in Congress has rejected every one of these thoughtful proposals.

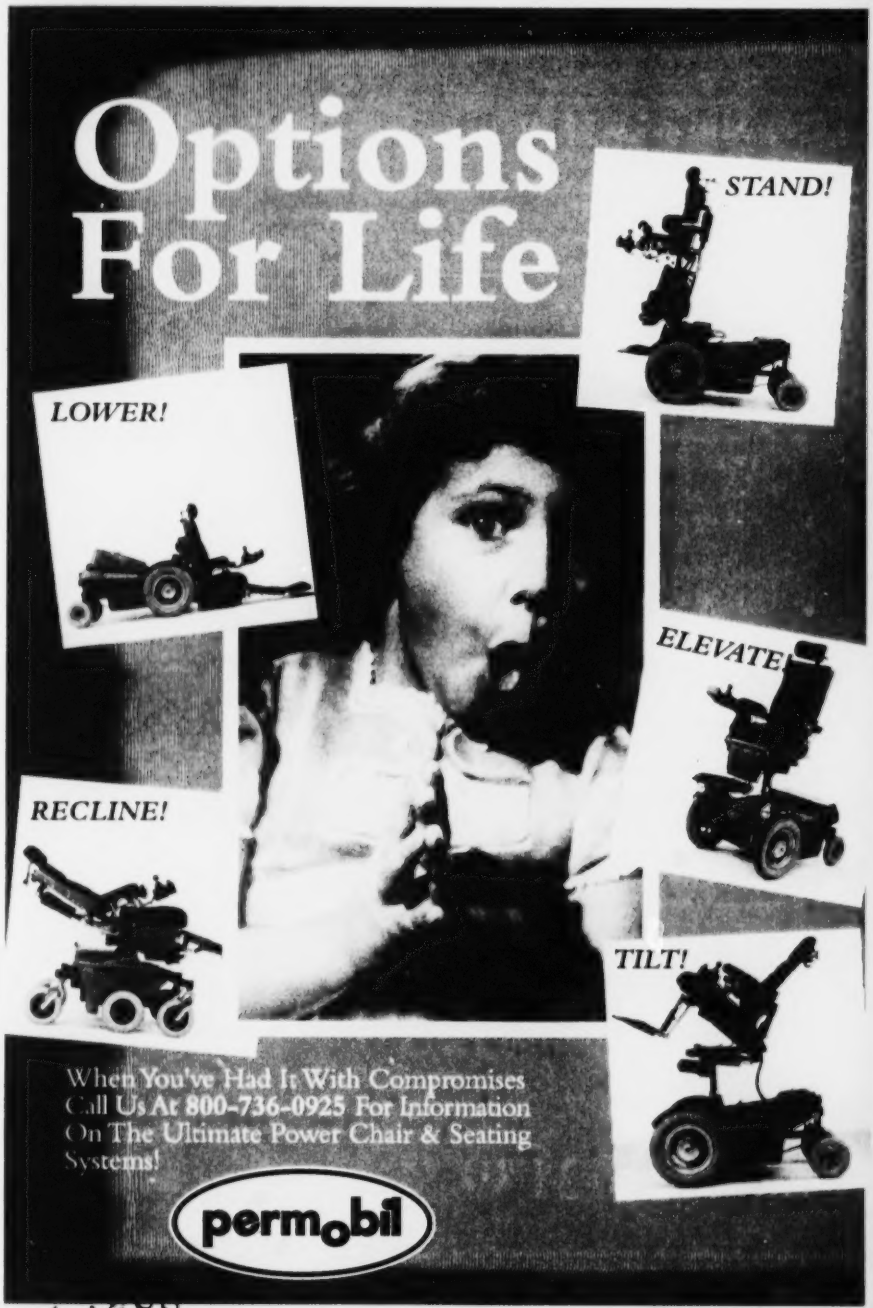
Instead, Medicaid cuts proposed by Republicans would force states to slash services. The first to go would be services such as personal assistance and assistive technology. And this is just the beginning. By 2002, these Medicaid cuts would eliminate coverage for nearly nine million children, elderly people and individuals with disabilities.

Fighting for the future

What would these cuts really mean? A few weekends ago, someone asked me this very question. The questioner was a contemporary of mine, a woman with very significant physical disabilities who relies on augmentative communication like I do.

There was no sidestepping or sweet-coating the issue. I gave her the only honest and direct answer I could: These cuts, along with the power of the nursing home lobby, would mean that thousands of people with disabilities would be forced into nursing homes once again.

If there is one message I want you to take away, it is this: You and I are fighting for our lives, for our future and for the right to decide that future for ourselves. But most of all, we are fighting for the lives, the futures and the fundamental civil rights of our sons and daughters. **EP**



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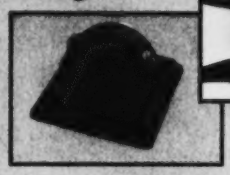

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Networking

Information from The National Parent Network on Disabilities

The National Parent Network on Disabilities Board of Directors

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Janet Vohs
Federation for Children with Special Needs, Boston, MA, *Secretary*

Patricia McGill Smith
Executive Director

Correction:
The Nevada Parent Training and Information Center (PTI) was listed incorrectly in the August issue of *Networking*. The correct listing is:

Nevada PEP
(Parents Encouraging Parents)
4970 Arville St., Ste. 110
Las Vegas, NV 89118
(702) 253-1939
(702) 367-9812 (fax)

NPND regrets the error.

IDEA Reauthorization Update

As EXCEPTIONAL PARENT was going to press, it became clear that the House of Representatives intended to consider and rewrite the reauthorization of the Individuals with Disabilities Act (IDEA) by the end of September. This makes House floor action—including debate, amendments and a vote on the reauthorization—likely to occur during October. The Senate is expected to make its version of the bill public no later than September 25, with deliberation, rewriting and possibly a vote before the end of October. Our children's access to public education will be decided within the next few weeks.

This installment of *Networking* will examine the proposed changes to the IDEA and their impact upon children and youth with disabilities. As it appears now, both the House and Senate versions of the IDEA would seriously erode the due process rights of children with disabilities. Call or write to members of your congressional delegation. You don't have to be an expert on the proposed legislation; you are an expert in the day-to-day real world. Your legislator may never have met a special education student. Share *your* expertise with Congress.

We must act now or we will have no right to complain about what we get. It is not too late to be heard, but whatever you decide to do, do it now!

VITAL ISSUES

• *Students' due process rights would be eroded in the guise of discipline.* Both the House and the Senate are proposing that students who bring "weapons" to school or behave in a way that is "potentially dangerous to themselves or others" be subject to an "interim, alternative placement." This language would allow a teacher or administrator to unilaterally decide that a student's behavior is "potentially dangerous," thus initiating a process parents could not stop. Immediately, the student in question would be put out of school for 45 days. During that time, a "team" (the IEP team, we hope; but the proposal is vague on this point) would review the student's behavior and overall performance and develop recommendations for his or her next educational placement.

If parents disagreed with those recommendations, they could trigger currently-existing due process procedural safeguards, which are designed to protect parents' right to participate in decisions about their children's education. (Due process begins with legally-established "administrative remedies." The first of these is an "impartial hearing," which concludes with the written decision of the hearing officer. That decision may be appealed, but if that appeal fails, "administrative remedies" have been exhausted and parents must turn to the courts.)

In the situation described above, a student removed to an "interim alternative placement" would remain there while due process ran its course. However, because in many instances the "interim alternative placement" would be home-schooling, these due process procedures could serve to keep our children at home—just as they were kept at home prior to 1975, when PL 94-142 was first passed. (PL 94-142 was the original special education law and the basis of what is now known as the IDEA.)

• *Parents would be constrained in their ability to recoup legal fees, even if they win in court.* Currently, if parents do not agree with the educational placement of their child, and can't get the situation resolved through administrative remedies, they can take the case to court. If in court, the judge rules in the parents' favor, the school district is required to reimburse them for their legal fees.

The House proposal would add restrictions to the reimbursement of parents' legal fees. For instance, if parents did not notify school districts 10 days prior to filing in court to contest educational placement, legal fees would not be reimbursed. The proposal would also allow the court to reduce fees if the judge determines those fees are higher than "prevailing rates," thus reducing the amount of money parents would be reimbursed, but not the amount of money they would pay. The court could also disallow reimbursement if the parents did not demonstrate "good will" in settling the matter before going to court. However, school districts would not be required to demonstrate that they acted in good faith or seriously attempted to resolve the dispute prior to going to court.

These proposed restrictions on reimbursement of legal fees would make it harder for parents to secure legal representation. Parents can't hire a lawyer if they can't pay for one, and for many parents, it would be difficult to pay a lawyer if those fees weren't reimbursed. The delicate balance of power that now exists between schools and parents would be tilted in favor of schools.

• *School districts would be allowed to factor in cost when determining placement.* Proposed language would allow school districts to factor in cost when determining placement for special education students; this is not allowed under current law. This could mean that special education students would receive the cheapest—not the most appropriate—services. School districts could reduce their budgets for special education and justify inappropriate placements on the basis of cost.

HOUSE PLANS TO APPEND IDEA TO THE EDUCATION REFORM BLOCK GRANT

NPND has also learned that the House Economic and Education Opportunities Committee intends to

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append amendments of the IDEA to the House version of education reform—the Education Reform Block Grant. It is common practice to modify one piece of legislation by appending amendments onto another piece of legislation. Tying an amendment to a larger bill that is sure to pass assures that the amendment also will pass. For instance, appropriations (budget) bills often include amendments that have nothing to do with appropriations. Those amendments pass, however, because defeating the amendments would require voting against the entire appropriations bill.

With the IDEA, the House majority has reversed the strategy. They are attempting to gain passage of their version of education reform by attaching the IDEA reauthorizing amendments to it. The assumption is that the IDEA reauthorization is sure to pass, thereby pulling education reform along with it. House staffers have made it clear that they are pursuing this strategy in order to force the Senate into negotiations on education reform. If the IDEA were not attached to the Education Reform Block Grant, the Senate could pass the IDEA while avoiding education reform. This strategy in no way strengthens the IDEA's content, nor does it increase the likelihood of quick and easy passage.

NPND opposes holding the IDEA hostage to a bill that is controversial, and has forwarded a letter to this effect to the House Economic and Education Opportunities Committee staff. We do not think that this reverse strategy will necessarily work. Usually, amendments added to unrelated bills are minor adjustments. These IDEA amendments are not minor. These amendments fully embody the reauthorized law governing our children's right to a free, appropriate education.

By the time this article is published, it is likely that the House will have already acted on the IDEA. The bill will be going to the Senate Labor and Human Resources Committee. Contact the senators on this committee immediately, and tell them to reject any legislation that includes the IDEA reauthorization amendments. Committee chair is Nancy Kassebaum (R-KS); members are Spencer Abraham (R-MI), John Ashcroft (R-MO), Dan Coats, (R-IN) Mike DeWine (R-OH), Christopher J. Dodd (D-CT), Bill Frist (R-TN), Judd Gregg (R-NH), Slade Gorton R-WA), Tom Harkin (R-IA), Jim M. Jeffords (R-VT), Edward M. Kennedy (D-MA), Barbara A. Mikulski (D-MD), Claiborne Pell (D-RI), Paul Simon (D-IL) and Paul Wellstone (D-MN).

How to stay informed

The IDEA reauthorization is moving quickly. The bill's language and issues are changing daily. To be sure you have the most current information, contact your local Parent Training and Information Center (PTI). If you do not know how to reach that center, call NPND (703/684-6763). We'll connect you with informed parents in your state.

How to communicate your views

Parents are busy people. Yet the need to make our voices heard on these issues is critical, and the time is now! Due to the likelihood that the House will have acted by the time this piece is published, parents should concentrate communication efforts on their Senators. All members of the U.S. Senate can be reached by calling 202-224-3121 or writing to The Honorable Senator _____, c/o The U.S. Senate, Washington, DC 20510. We must make them hear us!

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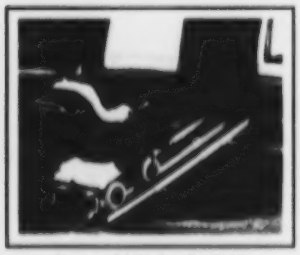

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CENTER FOR CHILDREN WITH CHRONIC ILLNESS AND DISABILITY

Children's Health Notes

MISSION

The Center for Children with Chronic Illness and Disability is learning a great deal about children with chronic illness and disabilities, their families, and the political, health care, and policy environments that affect their care. To reach as many families as we can, we join with *Exceptional Parent* to publish ***Children's Health Notes*** to define the environment, raise questions, identify strategies, or provide clarification of issues that are critical to providing care for children with special needs and their families.

Resident Training:

Pediatricians Make House Calls

Today, families provide most of the care for children with chronic illness and disabilities and they provide that care at home. Pediatricians can play a major role in teaching families how to care for their child's special health care needs, along with their "normal" developmental needs.

That's why pediatric residents at the University of Minnesota are learning about the chronic needs of children with disabilities from families. The classroom is the home and community.

The complex and long-term nature of chronic conditions typically require the involvement of a variety of family and community resources. While physicians see these children in the clinic and in the hospital, more often than not it is the families who negotiate their child's daily health and medical, educational and human service needs.

Two pediatricians at a time in their second year of a three-year residency spend four weeks in a neuro-developmental disabilities rotation learning about children with chronic illness and disabilities, and the impact of these conditions on the families who care for these children. Their time is divided among a variety of activities: home visits, community visits, in-patient and out-patient clinical care, and classroom discussion.

Resident Training
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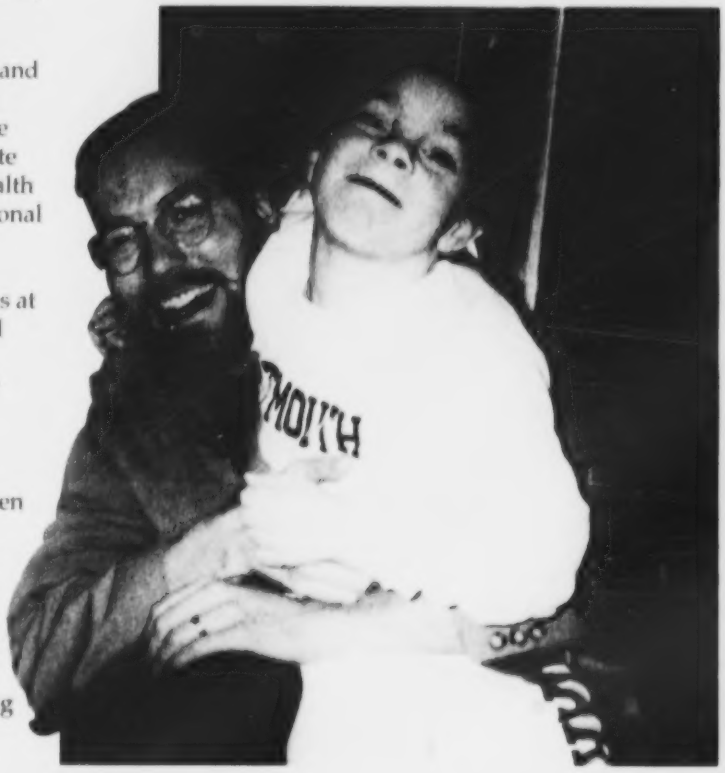
DEFINITION

Resident
A post-graduate physician receiving training in specialized areas such as pediatrics, family medicine, internal medicine, or surgery.



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Children's Health Notes

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Children's Health Notes
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(612) 626-4032 V
(612) 624-3939 TTY

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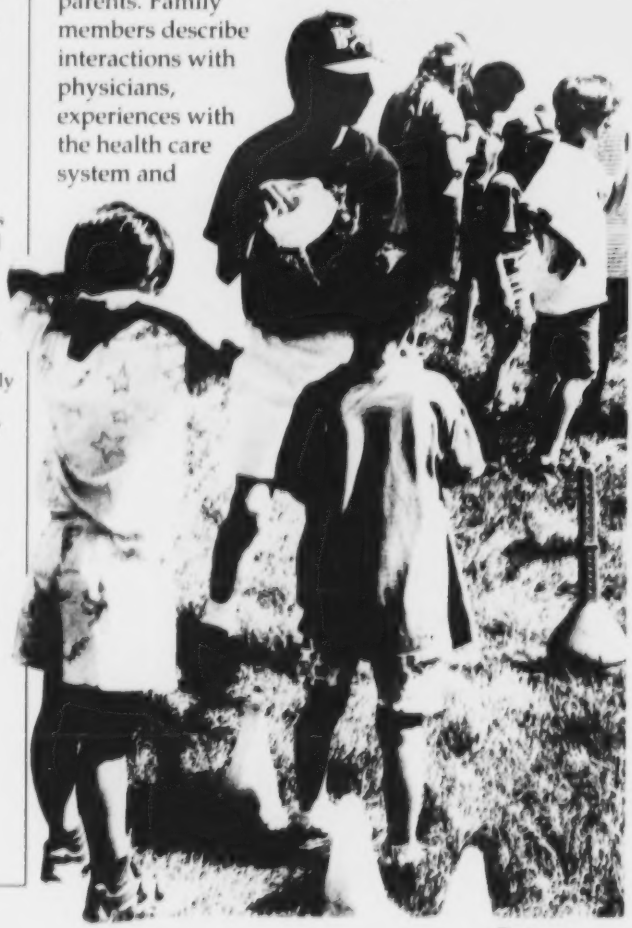
Home Visits:

The Parents-As-Teachers program allows residents to learn more about the daily challenges facing children with chronic conditions and how to coordinate care with families. Residents encounter a variety of experiences. A resident may attend the child's school, go out for dinner or go bowling with the family, or may learn about elaborate home medication regimens.

Before visiting with the families, residents view a videotape prepared by a group of parents. Family members describe interactions with physicians, experiences with the health care system and the impact of these factors on their lives.

- One family shows slides of activities at home which provide a rare glimpse into the life of a family who works endlessly to provide "normalizing" experiences for its children.
- One parent tells how she cringes when her deaf child is labeled handicapped or crippled.
- Another parent asks a physician, "How will you know when a parent is overstressed? What will you do about it?"

The videotape and the guided discussions that follow provide the background for home visits.



One resident says his family visit reminded him that parents with children who have disabilities are parents first. "Along with managing all those medications and adapting their lifestyle to accommodate their needs, they still cook the hot dogs, keep the kids from fighting, and do what all parents must do."

He goes on to say, "The children with special needs are children who need attention, direction and love."

Another resident recognized parents struggling with tough questions like, "What are the limits of my son's potential. How far do you push?" Most often, residents express how impressed they are with the family's resilience.

Like the residents, families often gain insights. One mother of a daughter with cerebral palsy writes: "I think it's a great program. I think the residents who participate in this will be better prepared than the current medical professionals who didn't have this opportunity and are uncomfortable with the disability or loss. Another mother reported that she would like to see the program expanded to include other experienced medical people, teachers, physical therapists, occupational therapists

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and other professionals with whom families work.

Community Visits:

Collaborating with families often involves coordinating care with community resources. Each month, the residents visit two fully integrated community sites in collaboration with the University of Minnesota's Institute on Community Integration. Ten community agencies, including early intervention and elementary school sites, community employment agencies and community recreation sites, participate. Residents learn about linking families with needed resources and coordinating care more effectively with the family, the health care system and community agencies.

These visits provide residents with a sense of the variety of resources available to children with special needs.

"What an eye-opening experience," one resident explained. Prior to this experience, few residents knew the extent to which children with disabling conditions could be included within the community and the school. One group of residents was struck by the range of physical development of the children in one school room but they were even more amazed by the wide range of functional abilities represented.

During the summer months, residents see kids at camp. Two physicians recall watching a child precariously being transferred from boat to wheelchair.

"All the kids came running out of the unstable boat and here was this counselor trying to keep his balance and get out while carrying a camper," Dr. Joseph-DiCaprio said. A mom herself, she wondered, "What would happen if the child fell in?" The question answered itself: What would happen if any of the children fell in?

"Maybe we are the ones who are afraid."

Rather than focus on what is wrong with a child and what can go wrong, as they must in order to understand the child's medical needs, residents are asked, "How can we strengthen this child's capacities?" This rotation allows the time for residents to discuss the roles they can play in the lives of children with disabilities and their families.

Clinical Encounters:

The rotation is based at Gillette Children's Hospital, a regional health center in St. Paul for children and adolescents who have disabilities. A total of 24 residents per year attend daily in-patient rounds and care for children with chronic illness or disability who are hospitalized, and children and families in a variety of clinical sites.

Classroom Discussions:

Discussions are led by facilitators who provide care for children with chronic conditions and who come from a variety of backgrounds, including medicine, nursing, social work, and psychology. Each facilitator meets with the residents to discuss key issues such as coordinating care with families and teaching them to manage chronic conditions.

Residents meet with a family psychologist to discuss how they can assess and promote healthy functioning in families. The facilitator who works with adolescents and parents in the community leads a discussion about normal developmental issues facing families during adolescence. The emphasis is on how physicians can promote healthy development in adolescents with chronic illnesses and disabilities during this time.

During the orientation to the community, residents are engaged in discussions about the function, organization, and role of interagency collaboration of the major community systems of support: health, education, human and social services. Residents then meet for a second seminar to discuss experiences and share their observations. They learn the differences between system-centered programs (like hospitals) and family-centered programs, and are shown that most often success really requires an interdisciplinary and interagency team.

On the last day of the rotation, residents discuss their experiences

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The intent of the Parents-As-Teachers program is to provide the trainee a realistic view of life and issues outside of the clinic setting.

1. **How does the family incorporate a child with a disabling condition into their regular routine?**
2. **How does the family create a positive environment for the child as well as for the rest of the family?**
3. **What are the special skills and competencies that a family develops in managing the often complicated care of their child?**
4. **What services and service providers are truly supportive of the family?**

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Building A Parents-As-Teachers Program In Your Community

Developing a Parents-As-Teachers program takes both patience and collaboration.

If you want to learn more about the Parents-As-Teachers program, contact:

Peter A. Blasco, M.D.
Associate Professor
Director,
Developmental
Disabilities Rotation
Box 721 UMHC
420 Delaware St. S.E.
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or

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612/626-4032

or

Celia Shapland, R.N.,
M.S.N.,
PACER Center
4826 Chicago Ave. So.
Minneapolis, MN
55417
612/827-2966

One of the developers of the program, Dr. Barbara Staub, a pediatrician, remembers answering an ad in a PACER newsletter in the fall of 1988. As the parent of a child with disabilities, Staub was interested in joining a group of parents and health professionals in a discussion of how they can better communicate with health care providers.

The group finally met in the fall of 1989. "We all agreed that doctors could do a better job of communicating with parents," Staub says. And after many phone calls and meetings, she and her Collaboration Among Parents and Professionals (CAPP) colleagues went on the road, making presentations to physicians and health professionals at Maternal and Child Health conferences and continuing medical education programs.

By August, 1990, "Parents-As Teachers" had found a temporary home in the adolescent health training rotation at the University of Minnesota after two successful years. The program was permanently incorporated in the developmental disabilities rotation.

If you are interested in replicating this program, keep in mind that the curriculum for both medical students and pediatric residents is crowded. Try to link up with a sympathetic physician and committed parent group. Together, you'll need:

1. A designated time when the trainee (medical student or resident) is focused on chronic illness.

2. A program director committed to organizing and coordinating the experience and incorporating it into related clinic and didactic activities.

3. A parent group committed to expending the time and energy to recruit and help organize participating families.

The **Center for Children with Chronic Illness and Disability** was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.

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in the Parents-As-Teachers program with the director of the disabilities rotation, Dr. Peter Blasco, M.D., and with the families they visited. Ordinarily, one parent from each family attends. The goal of this session is for residents and parents to communicate comfortably and openly with each other as they share the insights they have gained through the program.

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PARENT SURVIVAL MANUAL

PARENT SURVIVAL MANUAL: A GUIDE TO CRISIS RESOLUTION IN AUTISM AND RELATED DEVELOPMENTAL DISORDERS, edited by Eric Schopler, includes many practical suggestions for dealing with the day-to-day challenges of life with a child who has autism. The book was developed as a result of collaboration between parents and professionals, and is available from EXCEPTIONAL PARENT LIBRARY (800/535-1910). The following is an excerpt from Chapter 4: "Play and Leisure."

Changing the Game For Success

Children or adults with developmental disabilities may not enjoy particular activities because they are not successful at them. Sometimes, changing the equipment, the rules or the order in which the activities are done can make a dramatic difference in the individual's enjoyment.

Melissa has some physical coordination problems in addition to her autism. I was pleased that she was going to the bowling alley with a group of young adults. I thought the exercise as well as the company would be good for her. However, she found the bowling so confusing and difficult and did so badly that she started flapping and whooping until everyone in the place was staring. The next time they went, someone brought a three-foot-long aluminum ball chute that was set up at the line. Melissa didn't have to measure out her steps and swing the ball back, which was difficult for her. She just set it on the chute and pushed. It rolled and knocked down rows of pins to the shouts and cheers of her group. Melissa was the high scorer for the night. Now she looks forward to bowling, and the only gestures she has are "high fives" with a buddy when she bowls the pins over.

No one likes an activity in which there is no chance of success. A considerate person in the bowling group adapted the skill level needed to accommodate Melissa's limitations. She was then free to enjoy the success of bowling and the supportive company of her cheering peers. Here is another example of adapting equipment:

Our son, Danny, 5, does not like a traditional swing because his feet don't touch the ground when he is in it. He can't move the swing by himself, and feels uncomfortable when someone is pushing him and he can't stop the swing himself. So we hung a tire swing that he can lay across and propel with his feet still on the ground. He loves it!

Swinging was frightening for Danny because he was not in control of making the swing move or stop. After his parents adapted the swing, Danny enjoyed swinging more because his feet touched the ground and he was in control of the swing. He could also be more independent. Parents have always modified game rules for younger family members by moving the child closer to a throwing target such as a basketball hoop, a beanbag target or a dart board.

Sometimes, even individualized rule changes are helpful in adjusting an activity.

My son, Dwight, really wanted to play softball with his older brother, Mike, but he couldn't throw or catch well enough, and he could never hit the ball with the bat. He would fuss and whine when the kids wouldn't let him play. One day, Mike told Dwight that if he didn't talk to or touch the runner, he could run to the first-base coaching box every time there was a hit. Now when the older kids get a hit, he races along outside the baseline to the coach's box. He's really picking up speed, and the kids don't mind having him around now that he doesn't whine. They even practice playing catch with him now, so it won't be too long until he'll really be able to play ball (or join a running team) with kids his own age.

This brother was patient enough to find a way to involve Dwight in the baseball game and make it more enjoyable for both of them. Other rule adjustments that parents and teachers suggest include having everyone on the side get a turn at bat instead of retiring the side after the customary three outs. Table games and other less active games can also be adapted so that they are easier to take part in, but still enjoyable for everyone who wants to participate.

Bob, our 10-year-old autistic son, is the youngest of three closely aged children. The two older siblings often involve him in their games and activities by changing the rules or leaving out the parts that are too difficult for him. For example, in the commercial game "Sorry," a move can be spilt between two tokens—the number 7 can be completed by moving one token 3 spaces and another token 4. When Bob is playing, everyone completes his or her move with one token only. This is less confusing for Bob and makes game time more fun.

This family adapted a game for their son by changing the rules to fit Bob's way of learning and understanding. To eliminate confusion, everyone who was involved in the game used the same rules. The more concrete the rules are, the better an autistic person will be able to participate. **EP**

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Coming in November...

An excerpt from MEDICAL & SURGICAL CARE FOR CHILDREN WITH DOWN SYNDROME: A GUIDE FOR PARENTS. Written by 25 leading medical experts, this new book provides in-depth, easy-to-understand information on specific conditions that are common among children and adults with Down syndrome. This book is available from Exceptional Parent Library (800/535-1910).

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Health Insurance for Federal Employees

Plan maximums and "medical necessity"

Q My children and I are covered through a health insurance plan for federal employees. All of my children have pervasive developmental disorder (PDD) with autistic traits. They need ongoing physical, occupational and speech therapy. The insurance company has paid for these services in the past, but now they are balking. I've enclosed insurance company statements and copies of the correspondence between the insurance company and myself. Can you help?

A Your health insurance plan is a benefit plan sponsored by an association of federal employees rather than a traditional insurance policy. This means the plan is regulated under a law called the "Federal Employees Health Benefits Act," which establishes specific rules for claim appeals.

I've reviewed each Explanation of Benefits Statement (EOBS) you sent. Many of these claim denials are based on the grounds that the treatment "...exceeds the maximum allowed by the plan."

A representative of your plan told me that its rules regarding physical, speech and occupational therapy changed last year. Although plan participants apparently were notified of the change, you may not have realized its effects.

At this point, your benefit plan allows a maximum of 50 visits a year for physical therapy and a maximum of 30 visits a year for speech and occupational therapy combined. Any further treatments would be denied, and the explanation on the EOBS would probably be: "...exceeds the maximum allowed by your plan."

If you have not exceeded the plan maximum, you can appeal the claim denials on that basis. If you *have* exceeded the plan maximum, however, I doubt a claim appeal will be successful.

Many of your other claim denials are based on the grounds that the services "...are not covered expenses under the plan." That phrase has to do with the plan's definition of "medical necessity." It's important to understand that the plan isn't using the term "medically necessary" in an absolute sense; rather, it is working from its own definition.

Under that definition, your policy covers, for example, speech therapy "...to restore attained functional speech [lost] due to illness or injury," but not therapy "...directed at improving existing speech and addressing speech delay." On that basis, the benefit plan has concluded that your children's "...occupational, physical and speech therapy would not be medically necessary."

Your first step should be to review the denied claims, and the reasons for those denials, with a benefit plan representative. It's a good idea to have the EOBS in question with you during that phone conversation.

If that discussion does not lead to resolution, you can file an appeal. The "Federal Employees Health Benefits

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, *209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).*

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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Circle #107

Act" provides that appeals can be made only to the U.S. Office of Personnel Management. However, the maximum number of visits for speech, occupational and physical therapy and the benefit plan's definition of "medical necessity" are unlikely to change as the result of an appeal. (You can, of course, discuss these issues with an attorney.)

However, if your children are currently in school, and their participation in speech, occupational or physical therapy can be linked to possible progress in educational activities, such therapies can be specified in the children's Individual Education Plans (IEPs). School districts are legally obligated to provide all services listed on the IEP.

Many federal employees can choose from a variety of health insurance plans. Given the situation, it's important that you to begin to review the benefits offered by other available insurance plans before the next "open enrollment period." This period runs from the Monday of the second full work week in November through the Friday of the second full work week in December, or as otherwise announced by the U.S. Office of Personnel Management. Be sure to ask specifically about the insurer's definition of "medically necessity" in relation to speech therapy, and about specific limits to the yearly number of speech, occupational and physical therapy sessions. **EP**

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Ortho-Kinetics, Inc., Waukesha, WI 53187

Circle # 195

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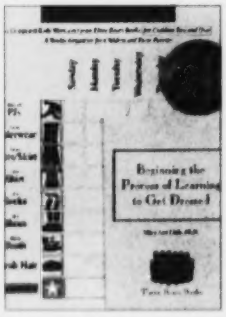

The *Competent Kids* series is designed to help parents and children face the every-day challenges of growing up. These books, charts, buttons and stars address specific developmental themes, ranging from learning about chores to learning to go to sleep alone. The activities outlined in the books and charts can be performed anywhere at any time, without equipment or instructions. Although the materials are classified by age level, conventional age labels may be less meaningful for children with significant developmental delays.

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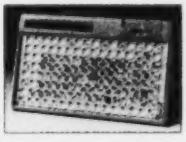
Circle # 196

DELTATALKER



DeltaTalker is an augmentative communication device that helps users communicate quickly and effectively. DeltaTalker comes with both digitized speech and synthesized speech. Digitized speech (recorded speech) makes it possible, for example, to introduce oneself, open conversations on the phone and sing songs. Synthesized speech (speech generated by a computer) allows the storage of a large vocabulary and the independent generation of new vocabulary items. Optional infrared capabilities (available early next year) will permit the user to operate the TV, VCR or other remote-controlled items.

Prentke Romich Company, Wooster, OH 44691

Circle # 197

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on Exceptional Parent's *"Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.*

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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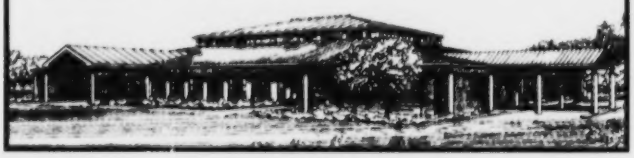

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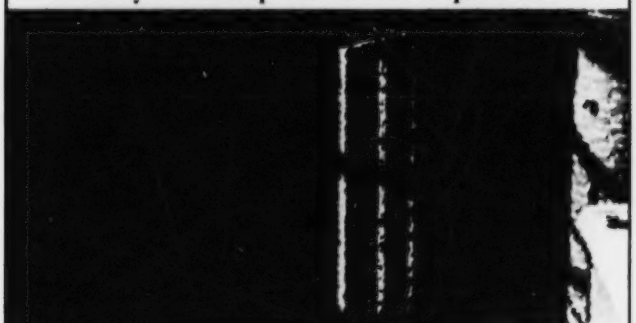

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ASK THE DOCTOR

by David Hirsch, M.D.

Unexplained Health Problems

Q Our son is now seven years old. He was born at 29 weeks gestation and had a complicated neonatal course. As a result of his prematurity and respiratory problems, he developed a grade IV interventricular hemorrhage (IVH), a bleeding into one or more of the small brain cavities that are necessary for the production and circulation of spinal fluid. Subsequent to this, he developed hydrocephalus (accumulation of the spinal fluid in one or more of the ventricles, causing expansion of the ventricle which results in excess pressure in the brain), cerebral palsy, epilepsy and optic atrophy (degeneration of the nerve to the eye, responsible for sight). He needs some help with feeding but does not have problems with choking.

For the first five years of his life, he was relatively healthy in spite of his disabilities. His seizures, too, were under good control.

In the last two years, however, he has had more seizures and frequent illnesses the doctors say are "viral," but from which he recovers very slowly. In fact, he seems to be sick more than he is well. He has had recent problems with constipation, too; this is also something new.

His doctor did a number of blood tests, including tests of his immune system. All the results were normal. X-rays of his chest and sinuses were also normal.

I am worried that these frequent illnesses will stress my son's heart and lungs. His doctors tell me it is normal for children with his type of chronic medical problems to have unexplained health problems. What do you think? Have my son's doctors looked far enough to find a cause for his problems?

A Children like your son, who have chronic medical problems, can be relatively healthy for many years. Unless there is an underlying heart or lung condition you did not mention, your son's illnesses should not cause heart or lung problems—unless he develops serious lung infections in the years to come. I wish I knew more about the specific type of infections your son has had. For example, were they just frequent colds or were they infections of a more serious nature, such as recurrent sinus infections, bronchitis or pneumonia? Without that information, it is hard to know whether the doctors ran sufficient tests to rule out any serious immune problems.

Did the doctors give you a reason for your son's increased number of seizures? Because he has hydrocephalus, I am assuming he has a shunt. Is the shunt working properly? His frequent viral infections might be responsible for the increased seizure activity, but other reasons such as inadequate medication or worsening of his hydrocephalus should be ruled out first.

Constipation is common in individuals with cerebral palsy because of lack of activity and an inability to bear down properly to have a bowel movement. This tendency to constipation may become a more serious problem if inadequate fluids are taken in because of the nausea, vomiting or fever that may accompany recurrent infections such as your son's.

It is hard to say when your son's condition will improve. But make sure he is getting a diet that supplies him with all the calories, nutrients and fluids he needs. Continue to work with his primary physician, who would be best able to coordinate the evaluations of any other doctors (specialists) involved in his care. Do not hesitate to ask questions and make the doctors aware of your concerns. **EP**

***In this column,** David Hirsch, M.D., a pediatrician and member of the* EXCEPTIONAL PARENT'S *Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mentions of specific products or medications illustrates suggestions; he is not endorsing any specific products.

Send questions to: ***Ask the Doctor,*** *EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-8742 (Fax).*

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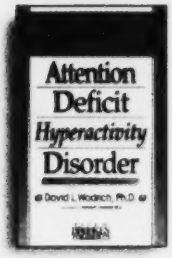

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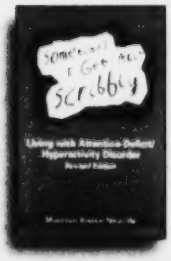

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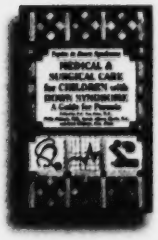

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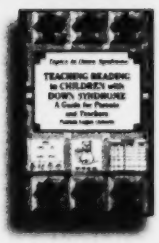

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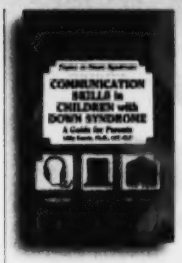

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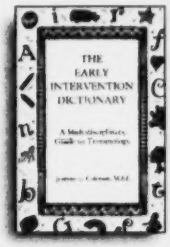

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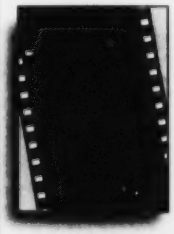

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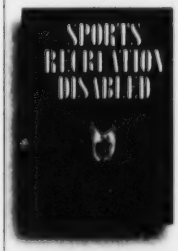

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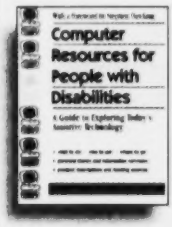

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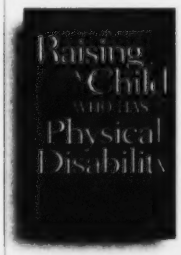

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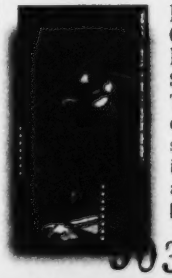

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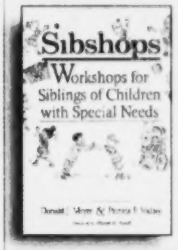

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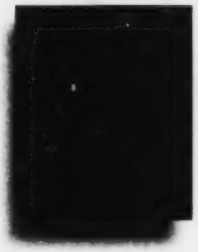

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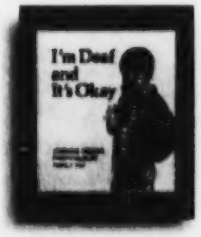

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WHAT'S HAPPENING

Toy Resources

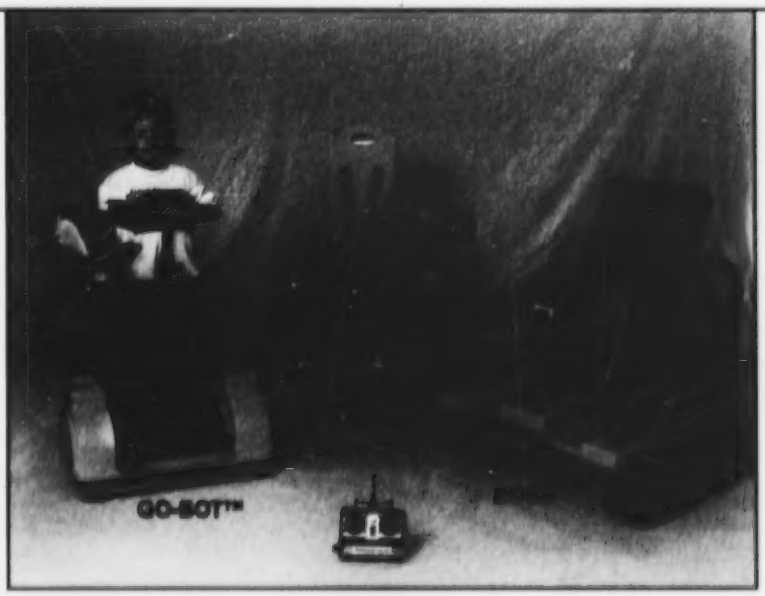
• The ***Guide to Toys for Children Who Are Blind Or Visually Impaired*** is a joint initiative of the Toy Manufacturers of America and the American Foundation for the Blind. The *Guide* provides pictures, descriptions and age ranges for 75 commercially-available toys that are especially appropriate for children with visual impairments. The 1995–96 edition features a greater selection of toys in a wider price range, including many lower-priced products; it also features a new category, "Books and Fun Skills." To receive single or multiple free copies of the *Guide*, send a postcard to Toy Manufacturers of America, 200 Fifth Avenue, Suite 740, New York, NY 10010. The postcard should say that you want the *Guide* and should specify the number of copies requested.

• The **USA Toy Library Association** (USA-TLA), a national network of toy lending libraries, serves children with and without disabilities. Depending on the particular program, families may borrow both commercially-available and specially-adapted toys. Both options may be helpful to families of children with disabilities; before purchasing, parents can determine whether their child enjoys and can use a particular toy.

USA-TLA helps people establish and promote toy libraries in local communities; distributes information on toy repair and discounts; provides research material on play, toys and early learning; and offers books, videos and a quarterly newsletter.

Some toy libraries charge a nominal membership fee. For more information, or to locate the toy library nearest to your home, write to USA-TLA, 2530 Crawford Ave., Suite 111, Evanston, IL 60201.

• **Lekotek Centers,** located nationwide, provide direct services, support and information to children with disabilities and their families. Primary



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According to his mother, Brooke, three-and-a-half-year-old Kody Rye is one Lekotek's happiest customers. Kody, who lives in Santa Barbara, California, especially enjoys playing with the single-switch, cause-and-effect toys.

Kody was born with holoprosencephaly, a rare brain disorder in which the brain does not divide into two cerebral hemispheres. Doctors told Kody's parents he would only live three to six months. "Three and a half years ago," his mom says, "I wouldn't have believed I would be writing an Exceptional Parent about the toys Kody enjoys."

Kody can hear and see, but cannot sit up, walk or talk. He has limited control of his head and hands. Kody has a "wonderful, happy spirit," Brooke writes. "He exhibits the enthusiasm of an athlete who has just run a race when he is able to master one of Lekotek's cause-and-effect toys."

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services include play sessions, focused on facilitating family interaction through play; toy lending libraries, filled with toys adapted to meet the special needs of children with disabilities; and the Compuplay program (available only at some Lekotek centers), which offers individualized computer training and playtimes with adaptive technology as needed. Many Lekotek programs are offered on a sliding-fee scale, with scholarships often available. For Lekotek centers that do not offer sliding fees, yearly memberships cost $50–180. Compuplay sessions are available at additional cost. For more information on Lekotek, call (800) 366-7529, voice.

• **The Lekotek Toy Resource Helpline** is a free service offering individualized assistance in selecting appropriate toys and play materials for children with disabilities. This service may be especially helpful for friends and relatives hoping to select appropriate holiday gifts for children with disabilities. From 9 a.m. to 4 p.m. (central time), individuals can reach the helpline by calling (800) 366-7529, voice.

House Establishes Disabilities Task Force

House Speaker Newt Gingrich (R-GA) has announced the formation of a House of Representatives Task Force on Disabilities. Gingrich appointed six House members to the task force: Bill Goodling (R-PA), Steve Gunderson (R-WI), Sue Myrick (R-NC), Jim McCrery (R-LA), John Porter (R-IL) and Mike Castle (R-DE). Also appointed was Andy Fleming, president and CEO of Paralympics and a constituent in Gingrich's home district.

The task force will coordinate legislative activities affecting individuals with disabilities to ensure that funds are directed appropriately and used in the most cost-effective manner. The task force is developing an outreach and communication strategy to gather feedback from constituents and to build successful community partnerships.

Gingrich stated, "With the help of this task force, I believe we can channel more assistance to those who truly need the aid, and less to government bureaucrats and those who are not truly disabled. The members will focus on removing disincentives to working, using innovative technologies to provide greater independence for persons with disabilities and increasing opportunities for the disabled to live and work in the community."

Gingrich is also launching a Task Force on Severe Disabilities in his home district, Georgia's Sixth. Eight of the 15 members of that group are individuals with disabilities or parents of children with disabilities. Gingrich adds, "Finding ways to help people with disabilities to become productive, working members of the community is not only good economics, but is morally right."

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Invited speakers for this conference include: Dr. Ralph Maurer–University of Florida, Dr. Diane Twachtman, Carol Gray, Richard Simpson–editor of Focus on Autistic Behavior, Nancy Dalrymple–University of Kentucky, Dr. Melvin Kaplan–Optical Therapy, Dan Crimmons, Denise Sawan Caruso–SLP/CCC, Lynette Scotese-Wojtila–OTR/L, Sean Barron, Dr. Max Wiznitzer–Rainbow Babies and Children's Hospital, and many more.

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On the day of his first big karate tournament, Barry pauses to flash a smile for the camera. With him are two of his biggest fans—David Lloyd, his instructor, and Clara Mills, his grandmother.

The Karate Kid

by Barry Atkinson

My name is Barry. When I grow up, I will be a black belt in karate. I have taken karate lessons for almost a year. I wanted to take karate lessons because I like Kung Fu movies and because I wanted to know how to protect myself.

I am an orange belt now. I take karate lessons two times a week. Sometimes I have group classes, and sometimes, I have private lessons. My teacher's name is David Lloyd.

Barry, who is very proud of a new earring that makes him "look like a real rock-and-roll star," is a big fan of Elvis Presley. "I'm learning how to play the guitar like the King!" he says.

I have spina bifida, which means I don't walk so great. When I first started lessons, I did karate in my wheelchair. But Dave said he wanted me to try to get out of my wheelchair. So I did. Now I do karate standing up like the other kids. Dave says I can do anything I want to do—even if I use crutches and have a trach. He makes me work hard, sometimes until I am sweating! I am the only kid at my studio who uses a walker. Dave doesn't care though; he even makes me do push-ups like the other kids.

Last spring, I was in my first big karate tournament. My grandma came to watch. I was the only kid with a disability, so I was kind of nervous. But I competed anyway, and I even won a trophy! Dave said he was proud of me. And I was proud of Dave for being my teacher. **EP**

Barry Atkinson, 11, lives with his foster family in Huntington Beach, California. He is a fifth-grader at Moffett Elementary School.

Parents' turn:

Our 11-year-old foster son, Barry, is a delightful child, who happens to have spina bifida with the Arnold-Chiari malformation of the brainstem and cerebellum, hydrocephalus, a gastrostomy-button and a tracheostomy. Barry spent his first seven years at a state facility for individuals with developmental disabilities, where he was often ill. Many people saw him as a sickly child who was too medically fragile to leave the hospital setting, let alone attempt any kind of sport.

But almost from the day Barry moved in with our family, he begged us to sign him up for karate lessons. We decided to give it a try, but were initially unable to find a studio that would consider accepting Barry. Though discouraged, we kept looking because Barry was so insistent. Finally, we found David Lloyd, a teacher at United Studios of Self-Defense, who was able to look beyond Barry's disabilities. Barry was welcomed with open arms from the first day of class.

Dave has never allowed Barry's disabilities to interfere with his training in karate. To help Barry keep up with his peers, Dave provides him with extra support and training in weekly private lessons. Dave pushes Barry to do all he is capable of, but also finds creative ways to adapt for Barry's physical limitations.

As Barry's strength and endurance have increased, he's moved from his wheelchair to a reverse walker and, finally, to forearm crutches. He hasn't missed one karate class yet due to illness! It has also been great to see Barry develop friendships with other students; he spends the first few minutes of each class greeting all his friends. Finally, and most importantly, we have seen huge leaps in Barry's self-esteem and confidence. We can't express how pleased we are with Dave and everyone at United Studios. They have made a tremendous difference in Barry's life!

—Mark Andrews & Ann Belles

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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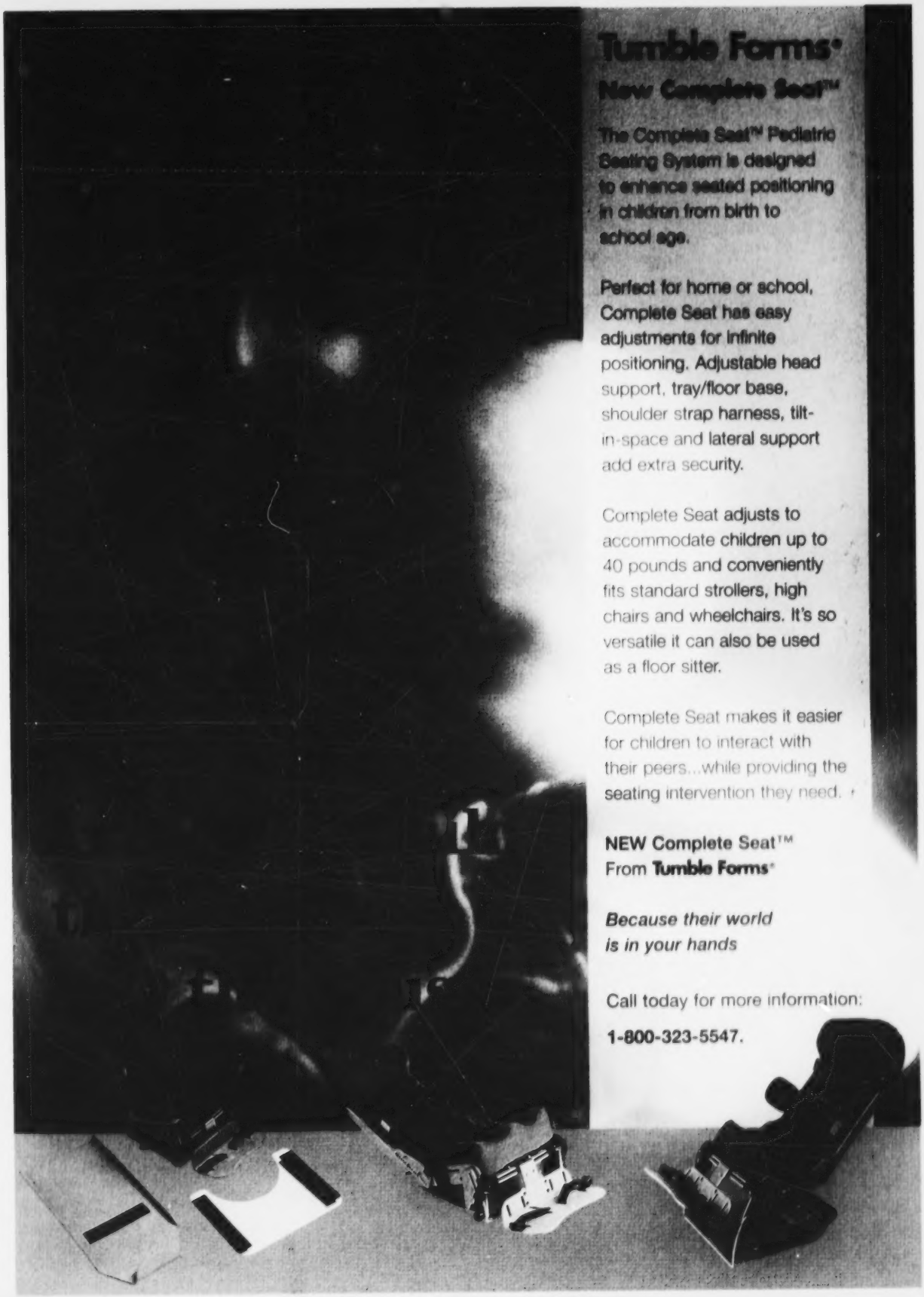

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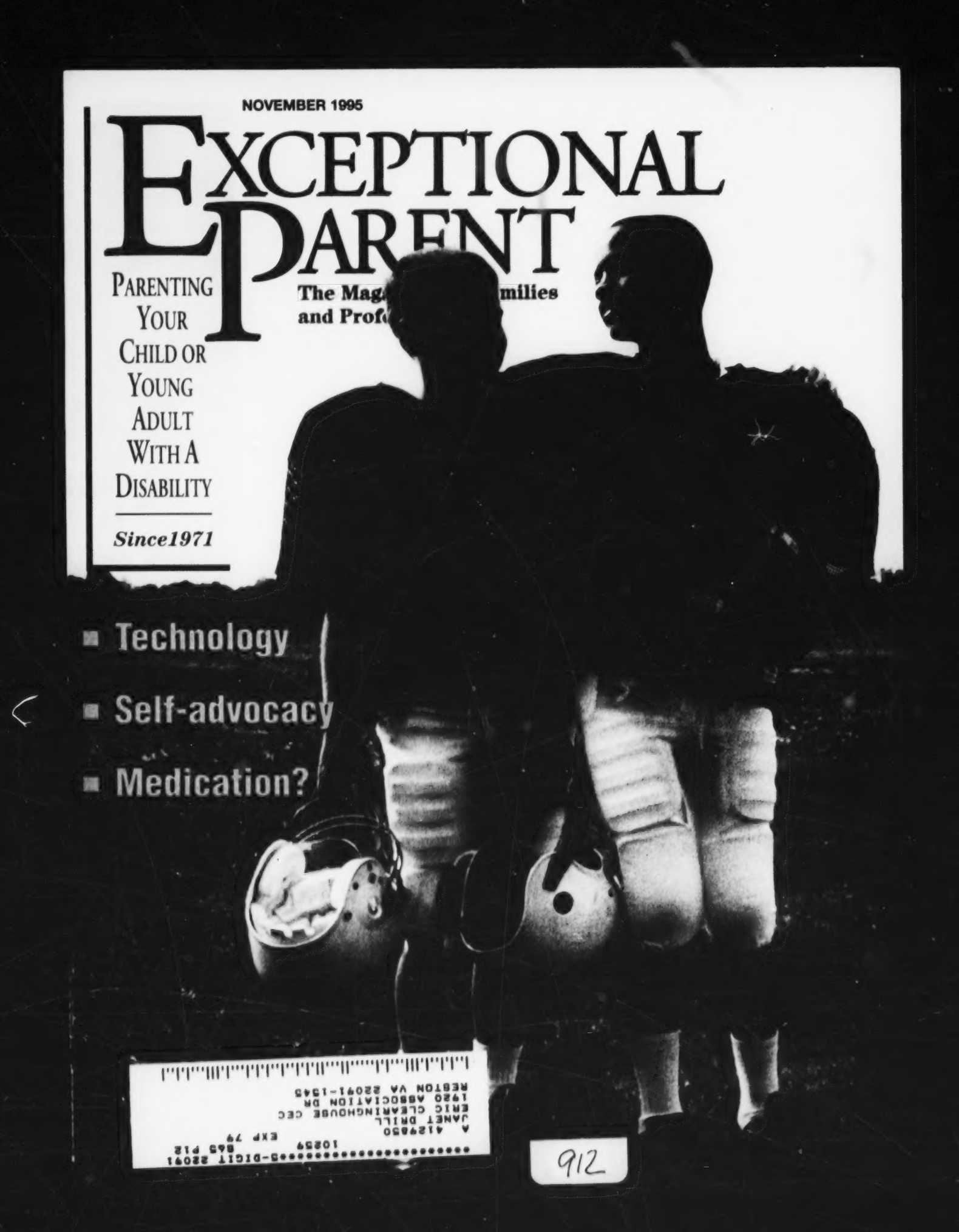

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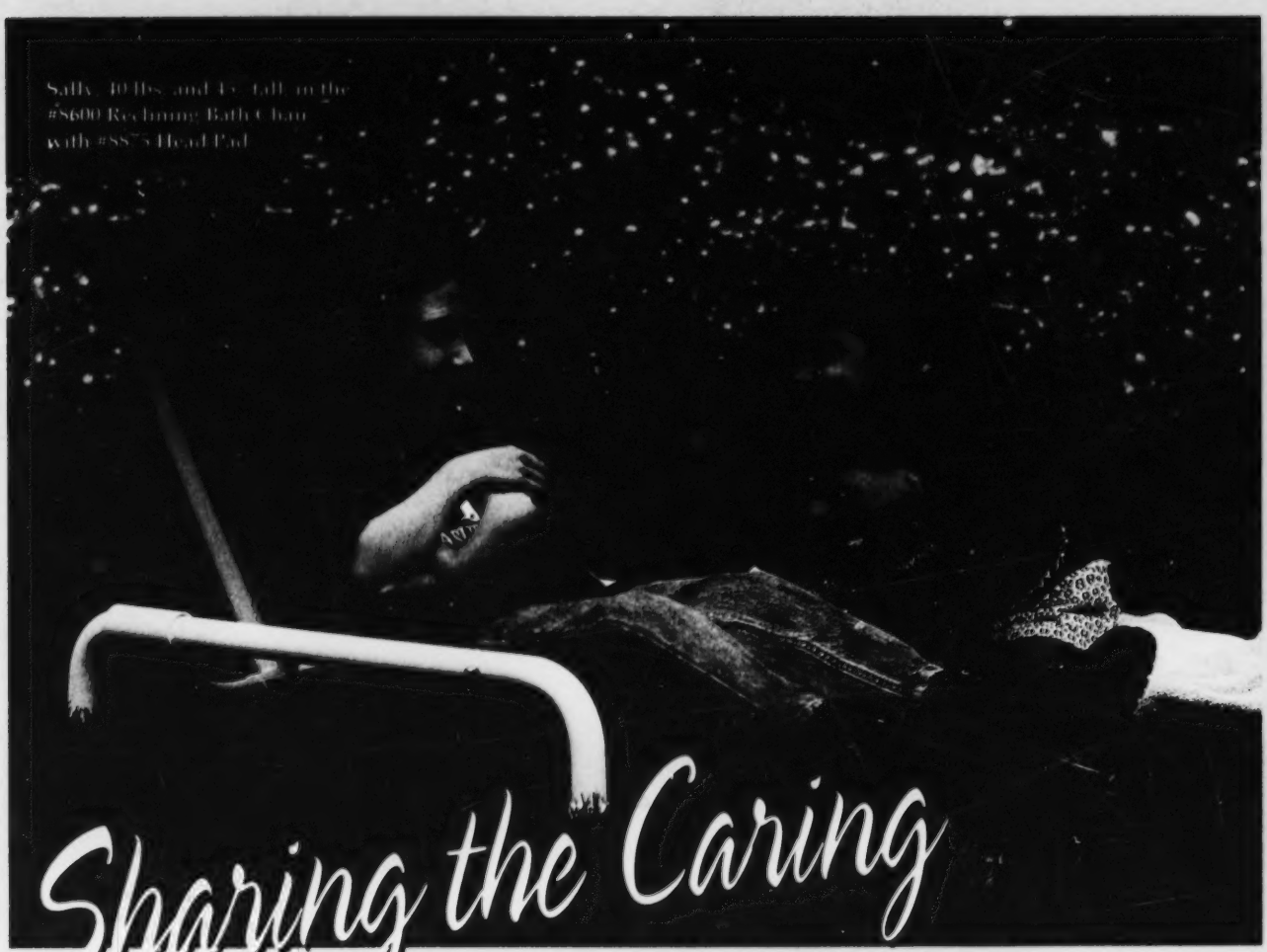

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The Magazine for Families and Professionals

NOVEMBER 1995 VOL. 25, ISSUE 11

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Cover: Twelve-year-old Justin Edwards (right) plays football for Savannah Middle School in Kinston, North Carolina, where he is a sixth grader. Justin has cerebral palsy and is non-verbal. Justin's mother, Parmilla, promised her son that if he was willing to train the teachers in his regular classroom to use his new augmentative communication (AC) device, she would support him in pursuing the activity of his choice. Justin chose football. When Parmilla and one of the coaches spoke on the phone, they decided Justin could be a manager and help his teammates during practice. Justin, listening from the other room, objected heartily. Repeatedly pushing the same button on his AC device, Justin told his mother, "Play, play, play!" Parmilla knew she couldn't go back on her promise and is glad she didn't: "I had the same fears other parents have—and I was also excited." Justin now plays on both defense and first string offense—as his coach says, "he has no fear." Justin lives in Kinston, North Carolina with his brother Samuel, 7, his parents, Parmilla and Spencer Edwards, and his aunt, Maryann Savage. He is pictured here with teammate Brett Houghton (left), 11. Photo: Lindsey Hall.

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EDITOR'S DESK

13th Annual Technology Issue

EXCEPTIONAL PARENT's first technology issue (1983) described how "newfangled" personal computers were beginning to impact the lives of individuals with disabilities. None of us could have predicted the contents of this year's technology issue! In this issue, several young people describe their on-line travels in the invisible world of telecommunications; they describe how this technology provides greater independence while preparing them for friendships in the "real world" of their "off-line" schools and communities. Other articles describe additional exciting uses of technology by children and parents.

STANLEY D. KLEIN, PH.D.

What will the future bring? We invited Alan J. Brightman to address this question. Alan has been at the forefront of the technological revolution for people with disabilities since the mid-1980s, when he founded Apple Computer's Worldwide Disability Solutions Group. His guest editorial takes us beyond thoughts of ever-better "gadgets" to the vision of a truly "connected" future.

Self-advocacy

"Self-advocacy" describes individuals with disabilities taking charge of their lives and educating others in ways that are as exciting as the magic of technology. This issue's *Role Model*, James Meadours, and other self-advocates were informative participants at a recent national meeting I attended. This issue's *Youth Connections* focuses on the same topic and features the voices of high school students with disabilities talking about the need to take control of their futures.

IDEA reauthorization

Many people have expressed concern about the future of the Individuals with Disabilities Education Act (IDEA). In "'Special Education' Deserves Special Emphasis," Rep. Randy "Duke" Cunningham (R-CA) may put some of these worries to rest as he describes clear, ongoing, bipartisan support for the IDEA.

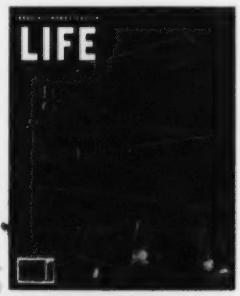
Health care concerns

At recent annual conferences of the American Academy of Cerebral Palsy and Developmental Medicine and the National Organization for Rare Disorders (NORD), I had the privilege of meeting parents, professionals and people with disabilities, and listening to their wonderful feedback about our magazine. Many also expressed concerns about the future of health care as "managed care" increasingly becomes the favored approach. At the NORD meeting, David Hirsch, our *Ask the Doctor* columnist, described his efforts to help managed care providers in Arizona understand the necessity of appropriate care for every child, including those with complicated needs. Next month, we will begin to present information about managed care and its implications.

EXCEPTIONAL PARENT had the privilege of collaborating with NORD to present its largest conference ever. Kim Schive, David Hirsch, Joe Valenzano and I participated as speakers and were able to meet informally with many readers, while members of our fine staff assisted the ever-energetic NORD team. This meeting was inspiring to all participants and a shining example of the difference one parent can make (in this case, NORD founder Abbey Meyers).

A "must read"

The November issue of *LIFE* presents a compelling cover story of men and women who served in the Gulf War, and who are now involved in a more complicated tour of duty—parenting children with disabilities and special health care needs. Regardless of our political opinions, these parents and children deserve our attention, love and support.



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For subscription and advertising information, see page 58.

BPA

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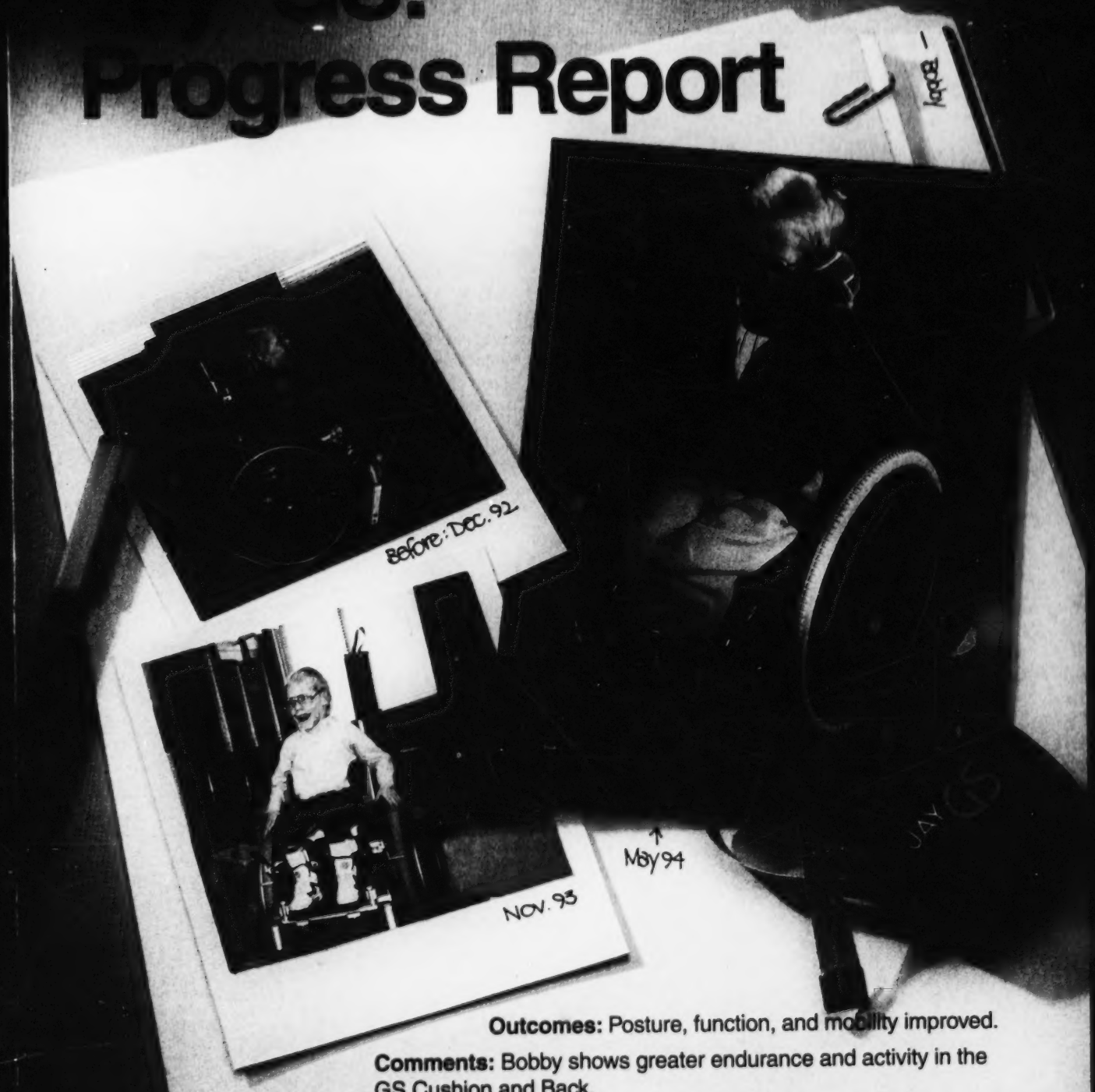
Progress Report



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LETTERS

Respecting Choices

I just finished reading the September issue. Thank you so much for the articles on educational choice. I was so happy to read that we are not the only parents who do not always agree with inclusion.

For several years, we dealt with a county and school district that wanted to treat our daughter just like any other "normally developing" child. That approach may be great for some children, but not for ours. Our hearts sank when the school district offered our daughter only an hour a week of individualized therapy—sessions that consisted mainly of playing peek-a-boo. And then they mainstreamed her into Head Start, and told us she would learn to function like any other child just by being left alone to wander around and observe.

We are very fortunate that we were recently able to move to a larger city, and enroll our daughter, now five, in a developmental preschool where she is receiving the one-on-one therapy and individualized attention she deserves. She is happy and thriving in this environment, learning more than she ever learned by being left alone to "observe" her "regular" classmates.

Thank you, EXCEPTIONAL PARENT, for the wonderful articles. And thanks to all the parents who stood up for what was right for their children!

K.H., Idaho

P.S. EXCEPTIONAL PARENT recently published our *Search* letter, and I wanted to let you know how pleased we were with all the responses. Thank you to all those wonderful, caring families out there!

■ Kudos on your September issue and the articles on educational choice! I support inclusion for most children, but not for my son. Those of us who do not believe inclusion is the "least restrictive environment" for our children are often made to feel like inadequate parents.

I'm glad EXCEPTIONAL PARENT depicted other points of view besides the prevailing sentiment that every child should be educated in the regular classroom. Inclusion is not for every child. It never has been, and never will be. Decisions about educational placement should be left to parents!

A.J., Ohio

These Ads DO Belong Here!

I strongly disagree with the letter from J.V.S. of Colorado (September 1995, "These Ads Don't Belong Here!") regarding EXCEPTIONAL PARENT's inclusion of advertisements from private educational and residential facilities.

My son, Stephen, is a beautiful, happy, social four-year-old who happens to have cerebral palsy—spastic quadriplegia with tremendous extensor tone (an abnormal pattern of muscle movement in which a child's body becomes stiff and straightens out). When Stephen lies on his back, his body becomes a rigid, 40-inch "board." I already have difficulty lifting, carrying and moving him to and from his wheelchair, standing frame, bed and play mat. Try to imagine what it will be like to do those things

continued on page 6

EXCEPTIONAL PARENT

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PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability, University of Minnesota, Minneapolis, MN
JEROME ROSNER, O.D., Professor of Pediatric Optometry, University of Houston, Houston, TX
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
B. J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
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PRODUCT NEWS

Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use. **Circle # 209**

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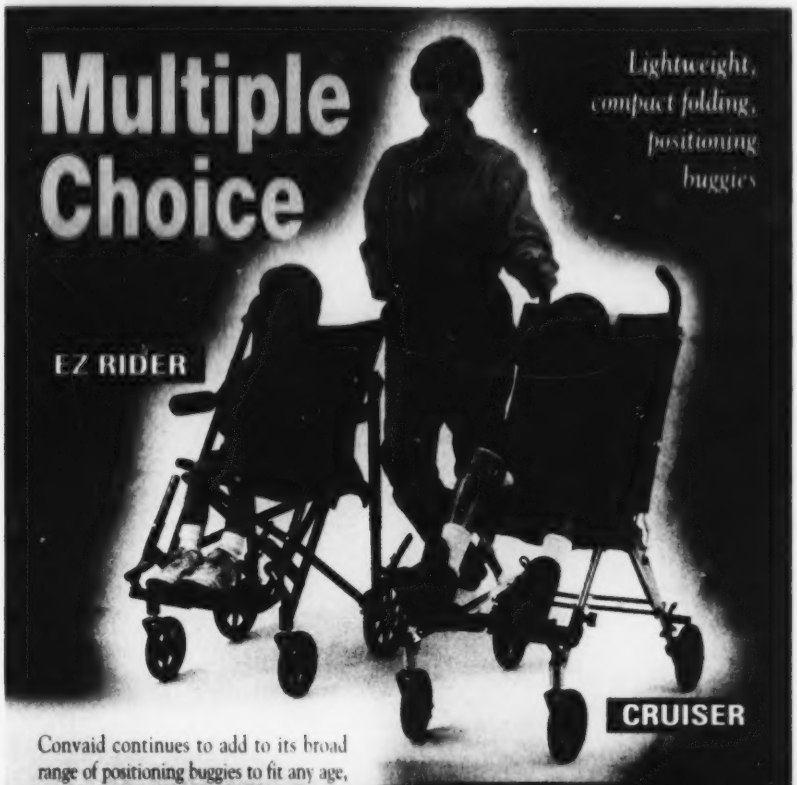

Convaid continues to add to its broad range of positioning buggies to fit any age, any size and most tight budgets. Choose from the Cruiser line with its many different positioning accessories, the EZ Rider with its quick folding design, or any of Convaid's compact folding buggies. Plus we offer the Cruiser Transport line, a bus/van tie-down successfully tested with up to a 170 lb. dummy.

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Circle # 126

continued from page 4

with the six-foot,165-pound adult my son will one day become!

I face the reality that someday I may no longer be able to physically manage my son's needs. In fact, I have already permanently dislocated a joint from lifting him. Therefore, it is a comfort to know, right now, that there are stimulating, interesting, attractive, activities-oriented, appropriately staffed facilities that may someday serve Stephen's needs. Frankly, without the knowledge that such places exist, contemplating the future would make me even more worried, nervous and guilt-ridden than I already am.

I implore everyone to understand that all children and their families have unique needs. Please look beyond your own situation and try to understand that these facilities serve a very real need for many people.

Thank you, EXCEPTIONAL PARENT, for continuing to support the concept of "choices" for parents and children. By providing us with a range of quality information, this publication helps parents and children to make good, informed decisions based on a thorough knowledge of all options.

Carolyn Dus
Michigan

Not Just For Parents!

Last year, when I began working at a school for children with developmental disabilities, I picked up a copy of EXCEPTIONAL PARENT for the first time. I loved it! I immediately ordered a subscription for myself and have enjoyed it ever since.

I am in college studying to become a special education teacher and have found EXCEPTIONAL PARENT to be an excellent resource. I learn so much from the articles. The magazine also gives me access to products and organizations.

Many times, when I read an article I can relate it to a child I have worked with. These articles give me a better understanding of families and the frustrations they face.

I just want to thank you for such a wonderful magazine, and thank the parents who take the time to write. EXCEPTIONAL PARENT is invaluable not only to parents, but also to professionals and teachers.

K.S., Colorado

Rhizotomy

The article "Selective Dorsal Rhizotomy" (August 1995) and the stories from families ("Go For It!" and "Evaluating Success") were interesting to me because my son, Dustin, had this surgery five weeks ago. Like Sean in "Evaluating Success," Dustin's spasticity prior to surgery was so strong it was difficult to hold him or get him into his wheelchair—he had an "extensor thrust from hell," so to speak.

Dustin has fought some valiant

continued on page 8

Circle #98

319

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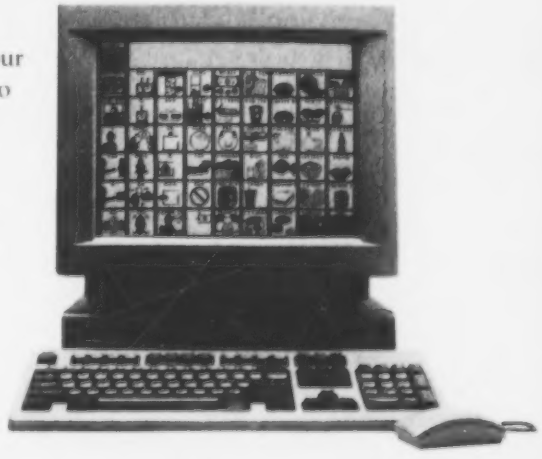

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920

Circle #161

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Circle #3

LETTERS

continued from page 6

fights with his spasticity. While in kindergarten, he wrote the article "Dustin's Trip to Space" (January 1990), using his letterboard. He continued in an integrated school setting until he was ten. He wrote stories, won writing awards, did well academically and learned Morse code as a backup to letterboarding.

However, as he grew older, and in spite of excellent seating evaluations, Dustin found it increasingly painful to be in a wheelchair. His spasticity caused him to push against the seat belt, which caused his skin to break open. I always had to move his computer switches around as his control site shifted when his pelvis moved forward in the chair. Thank goodness for Velcro!

By the time Dustin was 14, his seating problems were really out of hand. He needed to be repositioned three or four times during a short trip to the grocery store, and he had virtually lost his ability to bend in the middle. We feared he was becoming bedridden.

Here was my bright young son—a young man with terrific language skills, great motivation to communicate, enough computer equipment to launch the next space shuttle and a new power wheelchair—but unable to sit.

Rhizotomy held out hope. We were told Dustin was a good candidate because he was truly spastic and seemed to have some underlying muscle strength. We also had ruled out other options. Surgery would have been required to insert a baclofen pump, and I had spoken to an individual who had needed repeated surgeries before it worked properly. Likewise, Botox was not an option, because too many of Dustin's muscles were involved.

We were pleased with the rhizotomy experience. The pain control was excellent. Dustin was in the hospital for five days. He now has therapy at home three times a week. His sitting ability is amazingly improved. His comfort level is way up. And he is better able to control his computer.

Dustin's therapy sessions also have

continued on page 10

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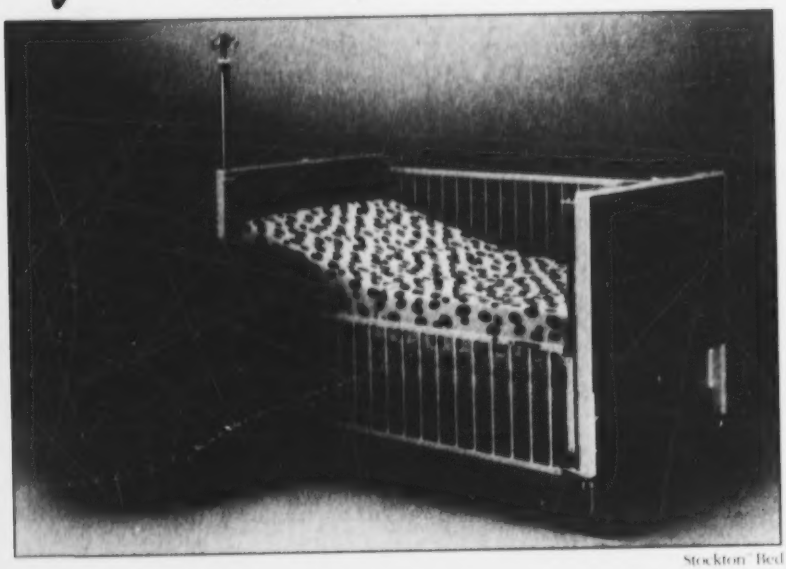

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Circle #156

continued from page 8

changed focus. Before the surgery, the goal of physical therapy was to reduce tone. Now the goals have to do with strengthening his muscles. Dustin's head and trunk are already showing real improvement. He is back on his three-wheeled bicycle and looks forward to horseback riding.

The ultimate goal has always been to build a system that would give Dustin access to mobility and communication. We had solved many parts of this puzzle. None of that mattered, however, if Dustin could not sit. In effect, he was all dressed up with no place to go.

How far will the rhizotomy procedure take Dustin? We still do not know. But I can say this much now: At the beginning of the summer, Dustin spent too much time lying on the couch. Today, he is going to see *Apollo 13* with friends.

Anne Webb, California

Adapted Physical Education

I was thrilled to see the June 1995 issue, which focused on recreation for individuals with disabilities and highlighted a number of recreation opportunities. However, I was dismayed to see no mention of a specialized recreation resource for students with disabilities—the field of adapted physical education.

I received my Ph.D. in adapted physical education from the University of Virginia. In fact, my dissertation focused on educating parents about the importance of physical education and fitness. My special interest in parents stems from the fact that I have a sister with a disability.

The law defines physical education as a direct service that is mandated for all students with disabilities. Not only are physical education services mandated, they *must* be adapted when necessary. Students with disabilities can receive specialized or individualized physical education services designed and implemented by a specialist in the field of adapted physical education. Adapted physical education is *not* a related service, so it should not be conducted by related-service personnel such as physical or occupational therapists.

Currently, all states have some kind of endorsement or certification in adapted physical education. There is a move toward national certification, meaning all physical education teachers interested in teaching students with disabilities may someday be required to obtain a national certification. On the local level, professionals at colleges or universities may be able to work with parents in doing individual assessments, itinerant teaching, attending case conferences and advocating for appropriate physical education services.

Because a student's health, fitness and motor skills are so vital in his or her transition from school to work, those of us in the field of adapted physical education feel very strongly that qualified individuals should be teaching students with disabilities. For years, we have strived to provide the most appropriate physical education services for individuals with disabilities. Our greatest challenge has been our anonymity.

Parents can request adapted physical education services only if they know about the field in the first place. Magazines like EXCEPTIONAL PARENT are vital in this education process.

Katie Stanton
School of Physical Education
Ball State University
Muncie, Indiana

EDITOR'S NOTE: To learn more about adapted physical education, send a self-addressed envelope with a 32¢ stamp to The Adapted Physical Activity Council/AAALF, 1900 Association Dr., Reston, VA 22091 (703/476-3430). You will receive information about the Council and information about ordering their publications.

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SEARCH

Goldenhar Syndrome, Esophageal Defects

My 19-month-old son, Casey, has been diagnosed with Goldenhar syndrome, a craniofacial disorder characterized by poor development of facial structures. He was also born with esophageal atresia (undeveloped esophagus) and tracheoesophageoal fistula, or TEF, meaning that he had an abnormal passage connecting his trachea (windpipe) to his esophagus (the tube that carries food from the throat to the stomach).

My husband is in the U.S. Army and served in the Gulf War. We wonder if our son's birth defects are related to the immunizations and medications my husband took to protect him from chemical exposure.

I hope to get in touch with parents of children with similar problems, especially Gulf War veterans.

M.M., Maryland

EDITOR'S NOTE: The following organizations can put you in touch with parents of children who have conditions similar to that of your son:

- *Goldenhar Syndrome Research & Information Fund, 8829 Gleneagles Ln., Darien, IL 60561; (708) 910-3939, (708) 910-4065, fax.*
- *TEF/VATER Support Network, c/o Greg and Teri Burke, 15301 Grey Fox Rd., Upper Marlboro, MD 20772; (301) 952-6837.*

In addition, you may want to contact the Association of Birth Defect Children (ABDC, 827 Irma Ave., Orlando, FL 32803; 407/245-7035). ABDC serves as a clearinghouse to provide free information about birth defects, particularly those thought to be associated with toxins. In recent years, ABDC has documented a variety of birth defects thought to be associated with parents' participation in the Gulf War. ABDC helps parents of similar children make contact with each other, and offers free participation in a national birth defect registry through a 24-hour, toll-free registry line (800/313-2232).

Krause-Kivlin Syndrome

My nine-month-old daughter was diagnosed with Krause-Kivlin syndrome at the age of six months. The syndrome includes brain anomalies; Alyssa has the Dandy-Walker malformation (a type of congenital hydrocephalus caused by a structural defect in the brain) and seizures. She also has several severe visual problems (glaucoma, microcorneas, cloudy corneas, no lenses and a short optic nerve on the right side), a ventricular septal defect (a heart condition in which there is an abnormal opening in the wall separating the left and right ventricles, or pumping chambers), a kidney defect (grade IV reflux) and failure to thrive.

Because this is a very rare syndrome, doctors have not been able to tell me what the future holds for Alyssa medically, visually or developmentally.

I would like to hear from other parents who have an older child with Krause-Kivlin syndrome or professionals who know a child with this diagnosis.

G.R., Pennsylvania

Galactosemia

Our five-month-old son has galactosemia. This is a rare, genetic, metabolic disorder characterized by an inability to metabolize galactose (milk sugar). Children with galactosemia may have mild to severe developmental delays, and may develop cataracts, kidney problems and liver disease. We would like to hear from other parents who have a child with this condition.

B.L., Ontario, Canada

EDITOR'S NOTE: Parents of Galactosemic Children (2871 Stagecoach Dr., Valley Springs, CA 95252; 209/772-2449, voice/fax) can provide further information on galactosemia, and can help you contact other parents of children with this metabolic disorder.

Biting Problem

My 18-month-old son, Ryan, was born with brain stem hypoplasia (the center part of his cerebellum is missing

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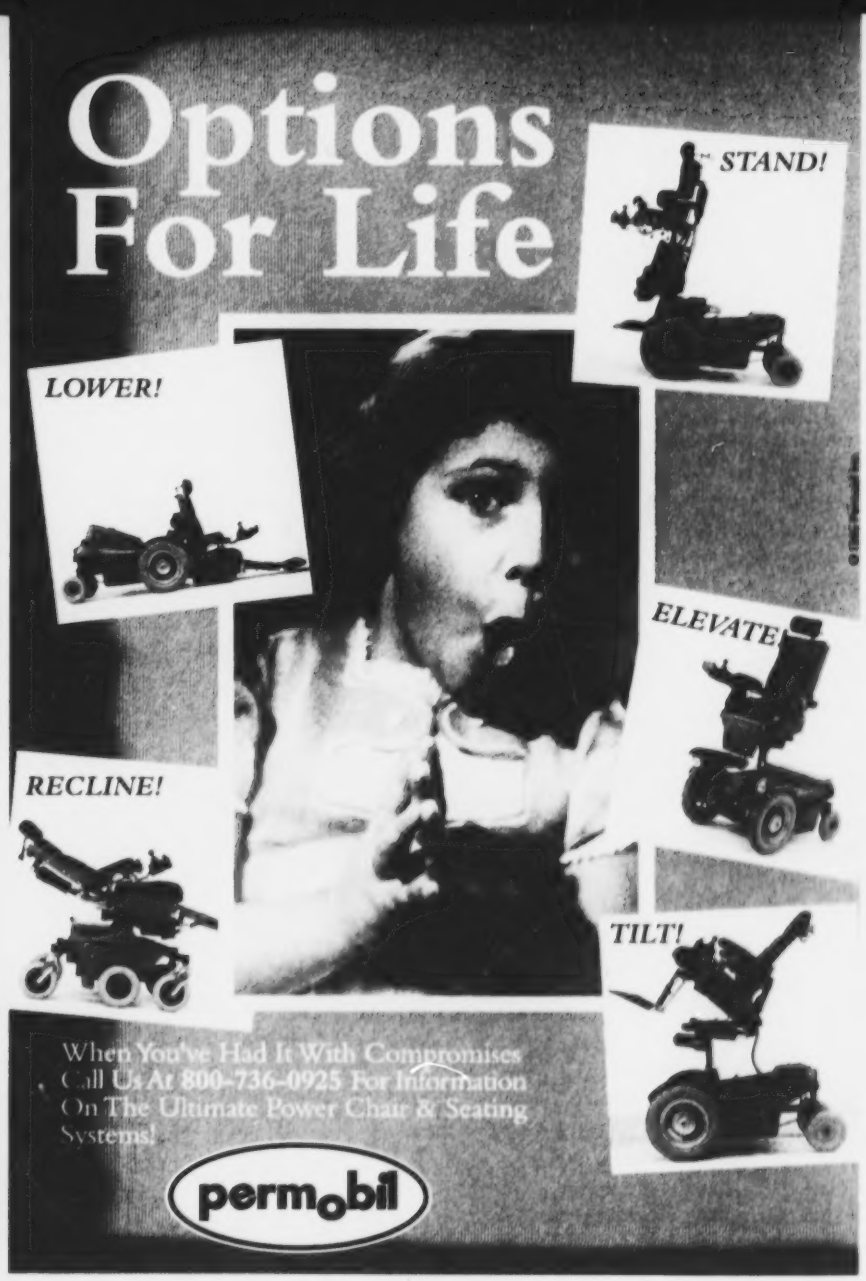

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Circle #117

SEARCH

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and his mid-brain is one-quarter the normal size). There is no known cause, but the result is third nerve palsy and Horner syndrome (a type of facial paralysis), affecting his right eye. He also has myoclonic seizures, mild cerebral palsy and probable profound mental retardation.

He can't hold his head up for more than a few seconds. Nor can he sit up, roll over, hold a toy in his hand or even smile. And he never ever cries.

What he *can* do is get his right hand to his mouth. This would be terrific except that he has a very strong bite reflex, so every time his fingers go into his mouth, he bites down—hard. Although he tries, he can't pull the fingers out of his mouth until the reflex is completed. By that time, his fingers are bleeding.

We've tried putting a slipper over his hand and fastening it around his wrist. That worked well for awhile, but now he bites his fingers through it and sometimes pulls it off. We've also tried taping his fingers around a rattle or teething ring, but he soon wiggles

continued on page 15

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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For product literature and advice, a free sample and information where DIAFOODS THICK-IT may be purchased, call... (800) 333-0003.

Circle # 211

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his fingers out of the tape. In addition, the tape is hard on his skin.

I would like to hear from anyone who can suggest a solution that doesn't involve restricting his arm movement. I'd also like to hear from parents of other children with profound mental retardation.

C.H., New York

Cohen Syndrome

Nicholas, now 15, was the first of our three children. He was initially diagnosed as "developmentally delayed, with speech and language impairments." Later, his diagnosis changed to Prader-Willi syndrome, but he eventually "out-grew" the characteristics of that disorder. Two years ago, he was finally diagnosed with Cohen syndrome.

Cohen syndrome is a rare genetic disorder characterized by low birth weight, mild to moderate mental retardation, delayed growth, obesity of the trunk occuring during middle childhood and muscle weakness. Children with the syndrome have an open mouth with prominent lips and upper central incisors. They are also very tall.

If your child has been diagnosed with this rare disorder or you know someone who has, please contact us. We want to know what the future may hold for our son in terms of education and employment.

A.R., Virginia

Calling 9-1-1?

My eight-year-old son has severe difficulties with speech. I am worried about what would happen in the case of an emergency that required him to use the telephone to summon help. I can teach him to dial, but he wouldn't be able to give his name, address or any other information to the 9-1-1 operator.

I have talked with other parents whose children's disabilities involve speech. They all have the same concerns. I would like to hear from anyone who has found a solution to this problem.

B.L., Pennsylvania

Chromosome 11q-

At three weeks of age, our 11-month-old son was diagnosed with a chromosomal abnormality involving a partial deletion of the long arm of his eleventh chromosome. His symptoms include craniosynostosis (premature fusion of one or more plates in the skull), development delays and heart defects. Only 33 cases of this condition have been reported since its discovery in 1973.

One networking organization (the National Organization on Rare Disorders) has been unable to help us make contact with another family dealing with this disorder. We are hoping to find such a family among the readers of EXCEPTIONAL PARENT.

J.B. & E.B., Louisiana

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Circle #33

RESPOND

Colorful Brace Stockinettes

E.L. (May 1995) has a four-year-old daughter who wears bilateral KAFOs (knee-ankle-foot orthoses) and uses "brace liners," cotton stockinettes that absorb perspiration and prevent the plastic of the braces from sticking to her legs. E.L.'s "fashion-conscious" daughter would prefer more colorful leggings, but tights make diapering and toileting too difficult. E.L. was seeking a source for purchasing colorful brace stockinettes.

When my daughter, Amanda, wore orthotics, we also had trouble finding socks she liked. One solution turned out to be ordinary boys' tube socks. We bought them in a large size so they went up to her knees. There were many advantages—tube socks were very inexpensive and readily available. They also wore well and stayed up.

Amanda was delighted to have socks in different colors. I was never able to find tube socks for girls, however, so our color selection was limited to darker colors like navy, red and black. Some styles have stripes, too. This may be a good way to supplement your daughter's wardrobe.

B.C., New Jersey

Swinging Objects

C.T. (April 1995) has a 10-year-old son with Down syndrome. He also takes Synthroid for hypothyroidism. Since a young age, he has had a tendency to focus on objects that he can hold and swing around. Often, as he swings the object, he talks to himself and, sometimes, spins in circles. At these times, he seems to "zone out." As he has gotten older, these behaviors have increased. C.T. was looking for suggestions to help her understand and lessen the frequency of this behavior, if not eliminate it altogether.

My 18-year-old son, Daniel, also has Down syndrome. When he was young, he liked to swing and twirl objects while spinning in a circle, usually babbling as he did so. Daniel outgrew these behaviors without any intervention.

As embarrassing as this behavior might have been to us, as strange as it might have seemed, I believe that these behaviors helped Daniel process people and events, particularly those that would otherwise have been overwhelming. If one listened carefully while Daniel spun and babbled, one could hear Daniel naming those events or people.

As I try to help Daniel find ways to cope with day-to-day frustrations now that he is 18, there are times when I am tempted to encourage him to start spinning around again.

A.K., New Jersey

Partial Trisomy of Chromosome One

S.P. and S.P. (May 1995) are the parents of a 16-month-old daughter, Ashley, who has partial trisomy of the first chromosome. They have been unable to locate any other children with this chromosomal abnormality and were looking for information about this condition.

My daughter, Erin, was born with partial trisomy one. She is now nine years old—I hope that gives you something to feel good about.

continued on page 20

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EXCEPTIONAL PARENT'S mission is to:

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practical guidance and support for parents, educators and professionals caring for children and young adults with disabilities and special health care needs.

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continued from page 16

When Erin was born, she was put in a special care nursery because her body temperature would not regulate. In that nursery, a heart murmur was detected and x-rays indicated a problem with her lungs. Her pediatrician suggested genetic testing.

When Erin was three months old, she was diagnosed with partial trisomy one. What stands out most clearly in my mind about that horrible day was the geneticist telling me that Erin would "probably die." She told us there were just six reported cases of the disorder. These six cases included two brothers who lived into their forties (they had no heart problems but had very severe mental retardation) and three girls who had heart problems; all three died by the age of 16 months. The sixth case was a sibling of one of these three girls who was diagnosed prenatally by amniocentesis and aborted. Since Erin had a heart condition like all the babies who died, the doctor did not give us any hope.

I lived the first 16 months of Erin's life wondering every morning if she would be alive when I walked into her bedroom. I always felt that if she could make it to 16 months, she would have "beaten" the others and would make it. But I was afraid to love her for fear that I would lose her. Eventually Erin's cardiologist heard about this and assured me that Erin's heart condition was so minor that, had she not been in a special care nursery, it would have gone undetected. But I have never forgiven the geneticist for those first horrible 16 months. And I have always hoped that somehow Erin's story would be an inspiration for another family.

You should see Erin today—she walks, she talks, and she has a sense of humor and a winning personality to match. She loves to swim, ride her bike and "trash" her bedroom. She has developmental delays but is 99 percent potty-trained, recognizes many printed words and knows the Pledge of Allegiance.

Erin attends a class for children with multiple disabilities within a regular public school. She is mainstreamed into regular third grade classes, mostly for socialization. She receives physical, occupational and speech therapies.

I hope that this letter brings you good news and hope. I would be so happy to talk with you at any time, and if I put Erin on the phone, I'm sure she would chat with you as well! I hope to hear from you.

K.A., New Jersey

Supervising a "Runner"

L.K. (August 1995) has a three-year-old son, Jimmy, who has autism. Jimmy is considered a "runner;" if he is not constantly supervised, he will run away. L.K. has tried using a tracking device, but Jimmy refuses to keep it on. L.K. wanted to know how other parents of "runners" deal with this problem.

I can't directly address the issue of running, but since my five-year-old son is also nonverbal, I share your concerns about identification during an emergency. In the wake of the Oklahoma City bombing, I began searching for a way of ensuring that a rescuer would be able to give an appropriate response. My solution was Medic Alert.

The Medic Alert Foundation (P.O. Box 1009, 2323 Colorado, Turlock, CA 95381; 800/344-3226) is a nonprofit organization that distributes personalized ID bracelets marked with a medical emblem and carrying a short phrase and a toll-free number. My son's bracelet says "multiple disabilities." Other possibilities might be "nonverbal," "autistic," "communication disorder" or any term you prefer. The type is small and not easily read by casual bystanders.

The toll-free number connects rescuers to the foundation's 24-hour database, which contains information you have provided. My son's information in that database includes his name, address, birth date, social security number and blood type; my name and my home and office phone numbers; and the name and number of a family friend. It also contains the priority message that he be transported to his "home" hospital, where he is well-known and where health care workers can access his records for a complete picture of his extensive medical and developmental history. This same information is printed on a wallet card, which I carry. (My son and I are not of the same race, so it's likely that in an accident involving multiple victims, rescuers would not immediately realize we are related.)

The Medic Alert cost is minimal, and qualifies as an IRS-defined medical expense. Information in the database can be updated at any time.

I've learned not to use the word "impossible," but the clasp on the ID bracelet is tricky enough to make it extremely difficult to remove, especially with one hand.

P.W., Illinois

■ My son also will "run" if given half a chance. To deal with the situation, we had an alarm system installed. The company was able to program it to beep any time any door or window is opened. This "beep" is not the full-siren alert that would sound in the case of a break-in occurring when the system is "armed." And, unlike the case of a full-siren, break-in alert, the monitoring company is not notified when a "beep" occurs. I'll admit that this beep can be annoying at first—especially when it repeatedly sounds as one is bringing in the groceries. But we've gotten used to the sound, and it has alerted us to our escapee on many occasions.

A Medic Alert ID bracelet was the other worthwhile investment we have made. The bracelet lists his diagnosis, name, phone number and the fact he has limited ability to comprehend speech.

K.G., Arizona

Tell us about...

... memorable family vacations.

The last vacation stories we published (April 1995) were such a big hit, we want to do it again. Share your stories and photos with other readers!

Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

S33

He's never gone on a sleepover before because he wets the bed.

(But tonight, with GoodNites,® that will change.)

For years, he not only had to stay home while his friends enjoyed sleepovers, he could never tell anyone the real reason.

But all that is about to change. Because tonight he has Pull-Ups GoodNites disposable absorbent underpants, the first ever for larger children. GoodNites come in two sizes designed to fit kids 45 to 85+ pounds. They're plain white, like regular underpants, and thin enough to disappear under pajamas. That way no one knows they're on.

Yet GoodNites are so absorbent – even more absorbent than before – they'll take care of any nighttime accident. So your child will wake up to clean, dry sheets; which means your child can enjoy sleepovers and vacations without worry.

It is estimated that some 3 million children—10 percent of all children ages 5 to 10—wet the bed more than once a week. The causes vary, so it's important that you visit your pediatrician. You could be in for some good news. But one thing is absolutely certain. Your child *will* outgrow bed-wetting.

In the meantime, use GoodNites.

GoodNites mean Good Mornings

Circle #133

Familiar Faces

You can't keep a good kid down! **Allison Twomey**, 9, climbs the slide at a local park while her dad, **Patrick**, spots her. Allison, who lives in Dixon, Illinois, with her parents and little sister Hannah, has congenital hypomyelinative encephaloneuropathy, a cyclical vomiting illness and Moebius syndrome. "Allison's legs and feet are still weak, and she spends most of her time in a wheelchair," says her mom, Cathy, "but she is constantly getting out of her chair and getting into things she never could before!"

Two-year-old Brendon Kelley loves to "help" with the laundry. Brendon, who has Down syndrome, lives in Cincinnati, Ohio with his mom, Valerie, dad Patrick, and big sister, Elizabeth. "Five surgeries and eight hospital stays have not dampened his spirit or reduced his curiosity," writes his mom.

The sky's the limit for aspiring pilot **Shaun Kelley**, a four-year-old from Kearny, New Jersey. Here Shaun tries his hand at the controls of the STAT Flight Medivac Helicopter in Valhalla, New York. During a recent stay at the Westchester County Medical Center, Shaun, who has hydrocephalus, was treated to "flying lessons" from the Medivac flight crew.

Krystal Miller, 4, of Alexander, Arkansas, uses her head to push a big, red switch that turns on her tape player. Krystal, who has spastic quadriplegic cerebral palsy, loves to tease her speech therapist by waiting until the therapist leaves the room to activate the tape player. "Krystal has surprised a lot of people by doing things they thought she never would," Her mother, Maggie, writes, "but I always had faith in her."

Heeeere's Nicky! **Nicholas Cugini**, 4, wows the audience every night in his living room in Houston, Texas. Nicky, who has cerebral palsy, lives with his parents, Rob and Eve. He attends an inclusive pre-school and loves coloring, Power Rangers and books.

Would you like to share a favorite candid snapshot or slide *of your child and/or family with other readers of* EXCEPTIONAL PARENT*? Send it to: Readers' Photos,* EXCEPTIONAL PARENT*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

935

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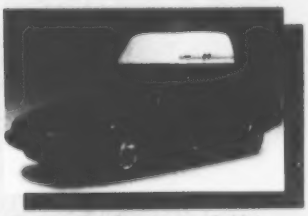

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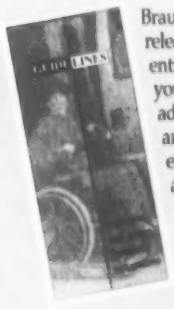

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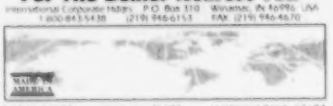

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Circle #112

Somebody

by Dave Jones

Dave and Jeff test a new HO-scale model locomotive, a Pacific Steam 462. Jeff operates the train's tranformer by using a head switch connected to a control unit.

I put my son to bed tonight, the same as I have each night for most of his 10 years. Tonight, Jeff had an ear infection, which made the job more delicate. I gently lifted him from his chair and laid him on the bed. Then I looked at him in a way I suspect other parents occasionally look at their kids—really seeing them for what they are, not the image or the dream.

As I lay Jeff face down on his bed, I watch my hands carefully straighten his feet and legs. I look at his hips, pulled up and to the right; his muscles take long moments to relax from sitting with a bar tight across his lap for the last few hours. As his hips settle to the surface of the bed, I straighten his back and move his shoulders to flatten his chest and free his arms.

I wait for Jeff to lift and turn his head to the left, so he can look at his tape deck, a major part of his bedtime routine. Later, he'll turn to the right, watch his night light, then sleep. On good nights, Jeff needs only one tape before he relaxes into sleep. Tonight, because of the ear infection, it may take several. The tubes in his eardrums seem to be part of the stuff kids like Jeff need. Fluids build up in his inner ears because he can't move his head around much.

Before I kiss my oldest child good night, I straighten his fingers and wrists and lay his hands out flat on the sheet. Jeff seems to like that and smiles at me. He's got a great smile—one that hooks therapists and ordinary folks on the street alike.

I pat his head and turn out the lights, checking the room quickly to see if I've missed anything that needs doing before tomorrow. I catch a glimpse of Jeff's night brace, neglected tonight because I refuse to subject him to two types of discomfort during the same evening. Besides, he needs a good night's sleep to help him recover from the ear infection.

Jeff, 8, celebrated Christmas 1993 with his four-year-old sisters, Taylor (right) and Megan (center).

Outside Jeff's room, I plug in the spare battery pack that hangs on the back of his wheelchair. It's not for his chair—we're still trying to find controls he can use to drive a power chair—but for his laptop computer and voice synthesizer. Many evenings, after plugging in the spare batteries, I enter the kitchen to find my wife programming Jeff's devices. She spends a lot of time making sure Jeff has everything he needs to function, both in and out of school. She also makes sure his devices include plenty of "fun stuff"—the material my son, the comedian, needs to "perform."

I hope Jeff stays dry tonight. He really likes to demonstrate some control of his world, a world in which he has dominion over so little. With a good start, he can time himself pretty well during the day at school; nighttime is more difficult. His toilet training has had its ups and downs, like so many other things in his life. We've learned to roll with the punches… sometimes. Other times, we punch back. Sometimes, it feels like we're taking swings in the dark.

Tonight is one of those rare occasions when Jeff's sisters are in bed before him. The birth of twins when Jeff was four was another adjustment in our lives. Now six, the girls have timidly started asking "Jeff questions." We struggle to agree on what to say and try to make sense of it for them. We've always tried to be honest about Jeff's birth injuries and what they mean. In many ways, Megan and Taylor are typical kid sisters who look up to and love their big brother. In school, they draw pictures of their family in six-year-old, stick-figure fashion. In each picture, the wheels on Jeff's chair are huge and Jeff is tall in the seat. There are a lot of smiles in their pictures. I like that.

I head downstairs. Maybe I'll write a bit, maybe watch some TV. After a while, I'll go to bed. Tomorrow morning, I'll be ready for the cleaning up, toileting, stretching and dressing that will begin another day with my son.

"Wouldn't it be nice," I think, "if—just for a few moments, maybe a few days—my kid could be just 'somebody' or 'somebody's kid,' instead of 'the kid in the chair?'"

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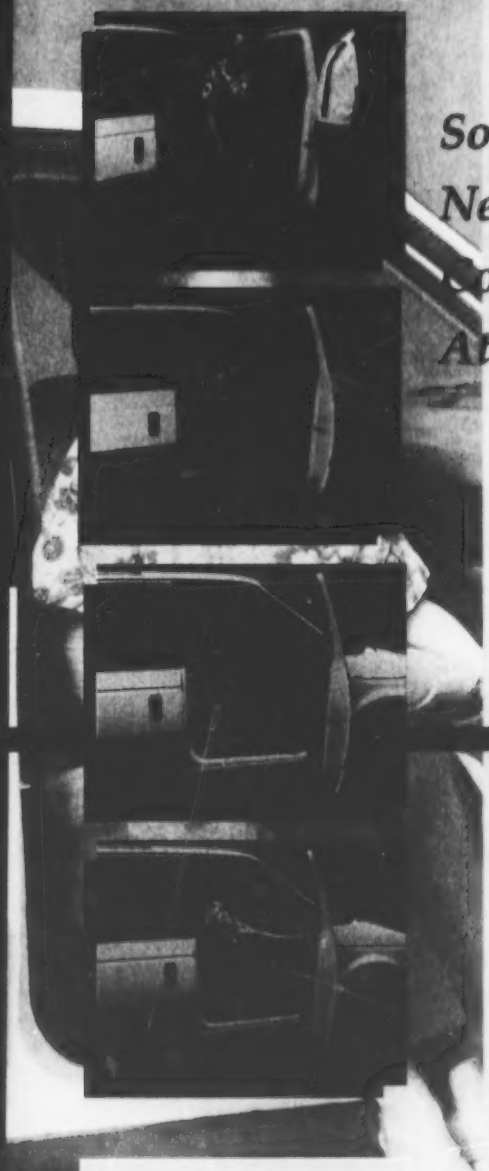
937

B R A U N



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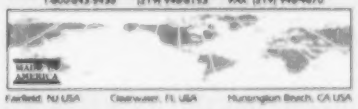

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Circle #272

In November 1994, Jeff and his friends marked his tenth birthday with a bowling bash.

continued from page 24

I wouldn't have to worry about the fast-approaching time when he's going to ask about himself. He's going to ask me, and I will answer him truthfully. My answers will be the only ones I can give, and Jeff will draw his own conclusions. He always has. **EP**

Dave Jones lives in Northbrook, Illinois with Stacey, his wife of 12 years. They have three children—twin daughters, Megan and Taylor, 6, and son, Jeff, 11. Dave is a physical education, dance and drama teacher at Pleasant Ridge School in Glenview, Illinois. He volunteers for the American Heart Association of Metropolitan Chicago, last year coordinating the Pleasant Ridge School's participation in the Jump Rope for Heart program, which raised almost $20,000. He also plays bass clarinet in the Northshore Concert Band, which has performed throughout the U.S., Canada and Europe.

In his spare time, Dave enjoys basketball, racquetball and working on a model HO-scale railroad. His rail system currently includes three trains; Dave is now working on the creation of three separate power systems to allow Jeff to operate individual trains with press switches.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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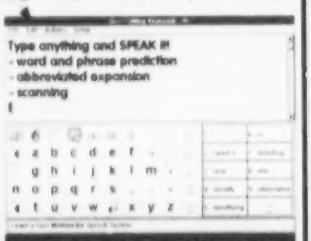

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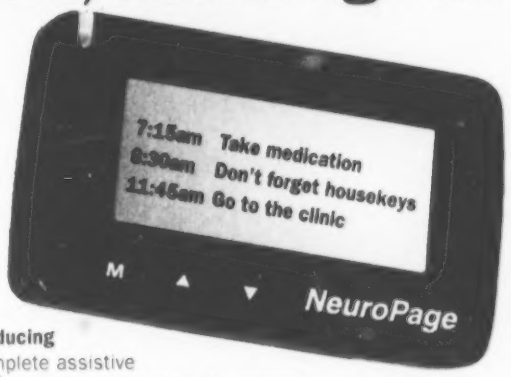

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Circle #278

The First Sleepover

by Jennifer Titrud

Maybe I'm old-fashioned, but I always thought I'd have a rule that neither of my daughters would have a sleepover until she was eight years old. That seemed a reasonable age. An eight-year-old probably wouldn't get homesick, nor would she be likely to become overly rowdy when it was time to settle down for the night.

That rule went right out the window when my second daughter, Laura, was born with a cloacal anomaly, a birth defect involving the digestive, urinary and reproductive systems. At the age of two, my older daughter, Emily, quickly learned all about "sleeping over" at her best friend's home. She participated in many hastily arranged overnight visits to accommodate Laura's frequent emergency trips to the hospital.

By eight, Emily was a veteran of sleepovers at the homes of several friends; she'd even reciprocated a few times. I was ready to concede that my "eight-year-old rule" had been too stringent, but how would I deal with Laura, now six and clamoring for a sleepover of her own?

I confess that I tried to sidestep the issue by using that old standby answer—"we'll see." I wasn't really surprised when this didn't work; children who have been through multiple medical problems and surgeries seem to end up with a particularly strong streak of persistence and feistiness. In no time at all, Laura had three friends who were begging their mothers to have her sleep over and, amazingly, three mothers who were saying, "Sure, no problem."

"Let's go, Mom!"
Overnight bag and favorite doll in tow, six-year-old Laura Titrud, couldn't wait to leave for her first sleepover at the home of her friend, Melissa.

No problem? Excuse me, but are you thinking of the right child? This is Laura Titrud. She spends her nights hooked up to a feeding pump and a bedside two-liter urine drainage bag attached to her urostomy pouch. And don't forget the nebulizer treatments. Then there's that little problem with bowel incontinence and diarrhea. Do you really enjoy starting the day with a few loads of laundry?

Much to my surprise, these mothers still answered, "No problem." We began to make plans, but over the winter one virus after another hit either Laura or one of her friends. We decided to wait until spring or summer.

Early in the spring, I had a thought: I wondered if Laura could be off the feeding pump for one night. At the time, Laura was taking in about one-third of her calories orally, and drinking water when thirsty. But if she could be off the feeding pump for a night, perhaps her urine output could be contained in the urostomy pouch. A sleepover would be a whole lot easier to manage without a feeding pump and bedside urine drainage bag.

One night I got up my courage and gave it a try. I'll admit I was alarmed when I saw how dark and scant her urine was the next morning—I have vivid memories of Laura as a very sick and dehydrated baby. But after emptying her pouch, Laura went straight to the sink and drank a big glass of water. Then she proceeded to rummage around in the refrigerator and eat up a storm. (This from the child whose first spoken sentence was, "I don't eat!") The experiment was such a success that, after consulting with Laura's doctors, we decided to try one night a week off the pump.

During the spring we also experimented with different enema programs. The idea of a sleepover became a real motivator for Laura because she realized enemas would help prevent accidents during the night.

In July, the big night finally came. All day long, Laura kept saying, "I can't believe I'm having a sleepover!" It was a

Jennifer Titrud lives in Fairfield, Connecticut with her husband, Blake, and daughters, Emily and Laura. Jennifer is the editor of PATHWAYS, *a resource publication of Parents Available To Help (PATH), a support network of parents of premature babies or children with medical problems in Connecticut and surrounding states.*

Laura, now 7, is a second-grader at Stratfield School in Fairfield. Over the past year, she's had several sleepovers and recently spent the night in a backyard tent with her dad and sister. Mom chose not to join the rest of the family for that particular adventure.

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Laura (left) and friend Melissa Flynn (right) enjoyed playing in Melissa's backyard.

triumph for her to feel such control and normalcy in her life. And I'll admit it—the sleepover was probably a much-needed break from an overprotective mother. I did stop by twice that evening to check on her, and I phoned at eight the next morning, but otherwise, I restrained myself admirably.

ALL DAY LONG, LAURA KEPT SAYING, "I CAN'T BELIEVE I'M HAVING A SLEEPOVER!" IT WAS A TRIUMPH FOR HER TO FEEL SUCH CONTROL AND NORMALCY IN HER LIFE.

I still break out in a cold sweat when I see my older daughter leave for a Brownie sleepover or watch my friend's sixth-grader go on a four-day field trip to upstate New York. *How will Laura ever manage those things?* Then I focus on the present again, and realize we have succeeded in making Laura's life as normal as possible. I'll continue to pursue that goal, and I know Laura will be pushing and prodding

Ready for "lights out," but that doesn't mean it's time to stop giggling.

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The Alliance for Technology Access (ATA) is dedicated to redefining human potential through the empowering application of technology for children and adults with disabilities. Now numbering 42 centers in the United States and Canada (see list beginning on page 43), ATA provides opportunities for people with disabilities, their families, friends, advocates and service providers to get hands-on experience with the ways assistive technology can enhance independence, achievement, productivity and quality of life. Working in collaboration with more than 70 technology developers and manufacturers, ATA centers are equipped to provide the latest information about available products and services.

The ATA is working to change the way people think about their own potential and the way they view technology—not as a luxury, but as an essential tool. Each center is ready to help potential users of technology become familiar with today's exciting technological advances. Through demonstrations, consultations, seminars and a myriad of other activities, more than 100,000 people each year are discovering new technologies that significantly enhance their lives. In the next few pages, we share a few of their stories....

Ann Moore
Technology breaks the cycle of failure

Ann Moore is a bright, popular 10-year-old living in Ormond Beach, Florida. Ann, who has spastic cerebral palsy and a severe visual impairment, attends Palm Terrace Elementary School, where she is an enthusiastic participant in her fourth-grade class.

But just two years ago, neither Ann nor her family could have imagined her current level of success and achievement. For six years, her parents, Beth and Bill, had worked with teachers and therapists to develop an appropriate educational program for Ann. Each year, the IEP team came up with an instructional plan to help Ann learn to communicate and demonstrate her understanding of classroom instruction. And each year, her parents, teachers and therapists experienced failure in helping Ann attain those goals. As often happens when failure becomes repetitive, expectations began to diminish.

Early in the summer of 1994, Beth and Bill decided to call CITE (Center for Independence, Technology & Education), the ATA center in Orlando. When staff members encouraged them to attend the CITE summer "computer camp" with Ann, Beth and Bill were inclined to believe the effort would be futile. After all, their daughter's school had all but given up on her, and Beth and Bill were beginning to lower their own expectations. But despite these doubts, Beth agreed to attend the camp with Ann and her older sister, Ellen.

Assistive technology allows 10-year-old Ann Moore to show her parents and teachers what she can do.

That summer turned out to be a turning point in Ann's life as her family explored new ways to communicate with her. CITE staff members assembled a wide array of communication devices and switches for Ann and her family to evaluate—everything from simple, switch-activated, battery-operated, three-selection scanners that allowed Ann to choose among three pre-recorded spoken messages with the touch of a switch, to more sophisticated devices like a Macintosh computer with Speaking Dynamically (Mayer-Johnson, Solana Beach, CA), a communication program that allowed Ann to create original sentences by selecting from a menu of pictures.

Beth and Bill had never seen equipment like this. Neither had Ann, but she responded enthusiastically. Almost immediately, Ann was able to use these devices to indicate her preferences.

Ann's parents left camp determined to make these new tools and ideas a regular part of Ann's daily life. Beginning with switches, they discovered that Ann, even with her limited hand movement, could operate a wheelchair-mounted switch quite reliably with her left hand. Soon she was using switch input to operate a Macintosh computer. She quickly progressed to Co:Writer, (Don Johnston, Wauconda, IL), word-prediction software that provided her with increased speed in writing and communicating. Because Ann has a visual impairment, she used Enlarge (Berkeley Systems, Berkeley, CA), a software product that provided her with large print on the computer monitor.

No longer did family members need to make guesses about Ann's likes, dislikes and choices. Now Ann could choose her own clothes and let her family know which videotape she wanted to watch. It was exhilarating to see Ann making so many choices, communicating her needs and desires, and, finally, demonstrating the knowledge and understanding her parents had always believed she possessed.

By the time school resumed that fall, Beth and Bill were full of ideas to share with the teaching staff at Ann's school. The school purchased a Macintosh computer and necessary access devices for

Ann's use. Not only did she begin to experience academic success for the very first time, thanks to the computer's speech output function, Ann also became able to communicate clearly with her teachers and classmates.

Each of Ann's accomplishments has encouraged her to attempt more. Ann's success also encourages her parents and teachers, who now realize that she is bright and can learn. "The Moore family has found a new hope for our beautiful daughter and sister," says Beth. "We found that hope at CTTE."

Lauren Scrivo
Technology makes inclusion work

Eight-year-old Lauren Scrivo of Fairfield, New Jersey has been a technology user much longer than most of her young friends. Lauren was born with congenital nemaline myopathy, a form of muscular dystrophy, and her parents, Linda and Peter, quickly realized that assistive technology could play an important role in her life. In fact, it was Lauren's preschool teacher who first recommended that the family visit the Center for Enabling Technology (CET), the ATA center in Whippany, New Jersey.

By the time Lauren entered first grade, she was doing all her writing with a mini-keyboard and computer. This worked well for some time, until, because of her disability, Lauren experienced a decline in her range of motion and hand strength. Soon just a small amount of word-processing caused fatigue.

By second grade, Lauren was unable to keep up with the writing demands of her class, demands her parents knew would only increase in higher grades. Lauren and her family returned to CET to search for solutions.

As Lauren and her parents tried out available combinations of hardware and software, they discovered two promising options. The first was Ke:nx (Don Johnston, Wauconda, IL), software that allows computers to recognize methods of input other than the traditional keyboard. One Ke:nx option displays a keyboard on the computer's screen. This allowed Lauren to do word processing by using a trackball—a device consisting of a moveable ball on a stationary base—to move the on-screen cursor. Since only small hand movements were required, Lauren was able to move the cursor around the on-screen keyboard quickly, and with little fatigue. But choosing letters from the on-screen keyboard required Lauren to push a button on the trackball, and this proved still to be too tiring.

The second option Lauren's family discovered at CET was the MagicWand keyboard (InTouch Systems, Spring Valley, NY). The small MagicWand keyboard responds to the light touch of two pens on the keys. This option required a very small range of motion and no pressure, so Lauren did not become fatigued while using it. And by combining the MagicWand keyboard with Co:Writer, Lauren was able to work even more quickly.

With CET's support, Lauren's parents worked with her school to purchase these important new tools and to provide Lauren with her own personal classroom computer. In addition, the school also made architectural modifications so every part of the building is wheelchair accessible. "Everyone at the school—from the principal on down—has embraced the concept of full inclusion and is committed to making Lauren's experience a success," says her mother. "We have nothing but praise for their efforts."

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The MagicWand keyboard, paired with word-prediction software, allows eight-year-old Lauren Scrivo to type quickly and with little fatigue.

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Jennie Shaw
Technology reveals hidden abilities

Assistive technology often reveals considerable ability where little had been assumed to exist. This was certainly true for Jennie Shaw, whose first encounter with a computer took place at the age of seven.

Jennie was born with an arachnoidal cyst on the left side of her brain. The cyst had clearly affected her fine motor skills, and she was also non-verbal. Jennie's occupational therapist referred the family to Technology Assistance for Special Consumers (TASC), the ATA center in Huntsville, Alabama.

To everyone's surprise, when seated at a computer keyboard, Jennie showed an immediate ability to type, even alphabetize, simple words. Her teachers had not even been sure Jennie was able to recognize letters. Jennie's mother, Vickie, began developing a vision of what her daughter might accomplish with technology.

For starters, it was clear that some type of augmentative communication (AC) device would be crucial. At TASC, Jennie was able to evaluate a number of devices. The Liberator (Prentke-Romich, Wooster, OH) was most effective.

Jennie celebrated her twelfth birthday with her augmentative communication device by her side.

Jennie's newfound communication abilities have helped her family and teachers learn more about her abilities. Her teachers now realize that when spoken instructions are also provided in written form, Jennie's comprehension improves remarkably. Jennie's reading abilities also surprised both family and teachers. Now 12, she reads at the ninth-grade level and appears to have been a very good reader for many years.

Currently, Jennie spends half-days in a regular third-grade classroom in her hometown of Fayetteville, Tennessee. She attends regular reading, writing, music, physical education and art classes, and spends the rest of her time in a classroom for children with learning disabilities. Her goals include being fully included in regular third grade social studies and science classes before the school year is over.

Anthony Notte
Technology is the equalizer

Anthony Notte, a bright five-year-old with spastic quadriplegic cerebral palsy, has been using computers since he was 15 months old. In fact, Anthony's family was referred to the Computer Center for People with disAbilities (CCdA), the ATA center in Shrewsbury, New Jersey, by professionals in Anthony's early intervention program.

Anthony's first speech therapist believed it unlikely that Anthony would ever be able to talk. It seemed reasonable to

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☐ Holzberg, Robert & Sara Walsh-Burton—**THE PARENTAL VOICE: Problems Faced by Parents With a Handicapped Child.** '95, 160 pp. (7 × 10).

Most all work in special education is focused on the child, his development status, his needs, his psychology, and the methodology required to educate him and develop in him the skills of independent living to the greatest degree possible. While the emphasis on the child is certainly required, in all the effort expended, parents have received very little attention. What happens to parents when their child is born with a severe handicap? What is the effect upon the marriage? How do parents deal with the emotional, social, and financial problems presented? How do they find services? What happens when services are far away or not even available? How does a severe handicap change parents and their attitudes toward their own child, toward the medical profession, and toward governmental authorities? This book attempts to answer these questions through the voices of parents themselves to give the reader a better understanding of the coping process. Parents from differing backgrounds and cultures present their personal accounts of how they dealt with their handicapped child from birth through adulthood. After each story there is an interpretation and commentary by an authority in the field of special education.

☐ Jones, Carroll J.—**CASE STUDIES OF SEVERELY/MULTIHANDICAPPED STUDENTS.** '93, 174 pp. (7 × 10), $38.95, cloth, $24.95, paper.

☐ Rakow, Sue F. V. & Carol B. Carpenter—**SIGNS OF SHARING: An Elementary Sign Language and Deaf Awareness Curriculum.** '93, 380 pp. (8½ × 11), 245 il., $47.95, spiral (paper).

☐ Fine, Aubrey H. & Nya M. Fine—**THERAPEUTIC RECREATION FOR EXCEPTIONAL CHILDREN: Let Me In, I Want to Play.** '88, 362 pp. (7 × 10), 9 il., 22 tables, $61.95, cloth, $34.95, paper.

☐ Sternberg, Les, Ronald L. Taylor & Jeffrey Schilit—**SO YOU'RE NOT A SPECIAL EDUCATOR: A General Handbook for Educating Handicapped Children.** '86, 172 pp. (7 × 10), $27.95, cloth, $15.95, paper.

☐ Smith, Margaret M.—**IF BLINDNESS STRIKES: DON'T STRIKE OUT: A Lively Look at Living with a Visual Impairment.** '84, 316 pp., $46.95, cloth, $29.95, paper.

☐ Pader, Olga F.—**A GUIDE AND HANDBOOK FOR PARENTS OF MENTALLY RETARDED CHILDREN.** '81, 268 pp., 2 il., 1 table, $38.95, cloth, $24.95, paper.

☐ Lowenfeld, Berthold—**OUR BLIND CHILDREN: Growing and Learning with Them. (3rd Ed., 2nd Ptg.)** '77, 260 pp., 7 il., $34.95, cloth, $19.95, paper.

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☐ Love, Harold D. & Freddie W. Litton—**TEACHING READING TO DISABLED AND HANDICAPPED LEARNERS.** '94, 260 pp. (7 × 10), 8 il., 23 tables, $51.95, cloth, $30.95, paper.

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☐ Hoffman, Cheryl M.—**COMPREHENSIVE REFERENCE MANUAL FOR SIGNERS AND INTERPRETERS. (4th Ed.)** '94, 314 pp. (8½ × 11), $41.95, spiral (paper).

☐ Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists.** '93, 382 pp. (7 × 10), 32 il., 8 tables, $75.95, cloth, $39.95, paper.

☐ Giordano, Gerard—**DIAGNOSTIC AND REMEDIAL MATHEMATICS IN SPECIAL EDUCATION.** '93, 320 pp. (7 × 10), 85 il., 26 tables, $59.95, spiral (paper).

☐ Jones, Carroll J.—**ENHANCING SELF-CONCEPTS AND ACHIEVEMENT OF MILDLY HANDICAPPED STUDENTS: Learning Disabled, Mildly Mentally Retarded, and Behavior Disordered.** '92, 294 pp. (7 × 10), 7 tables, $52.95, cloth, $31.95, paper.

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☐ Jones, Carroll J.—**SOCIAL AND EMOTIONAL DEVELOPMENT OF EXCEPTIONAL STUDENTS: Handicapped and Gifted.** '92, 218 pp. (7 × 10), $39.95, cloth, $24.95, paper.

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☐ Rose, Harriet Wallace—**SOMETHING'S WRONG WITH MY CHILD! A Straightforward Presentation to Help Professionals and Parents to Better Understand Themselves in Dealing With the Emotionally-Charged Subject of Disabled Children.** '87, 210 pp. (7 × 10), $37.95, cloth, $22.95, paper.

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continued from page 32

believe that a computer might be a part of an augmentative communication system he could use. Soon, however, his speech began to develop quite well. At that point, the focus of Anthony's computer use was shifted to written communication.

Soon Anthony discovered IntelliKeys (IntelliTools, Richmond, CA), an alternative keyboard with large keys that respond to a light touch. The keys can be configured in various ways for ease of use; for example, Anthony's first keyboard was arranged in alphabetical order.

But when Anthony became old enough to attend a preschool program, Joyce discovered that his teachers were completely unfamiliar with the assistive technology that had become "old hat" for four-year-old Anthony. The staff of CCdA worked with the family and Anthony's teachers to make the school district aware of his technology needs. The school district purchased the devices he would need and CCdA staff worked to familiarize school personnel with its use.

Now in kindergarten, Anthony is one of the most technology-savvy kids in school. He's moving away from IntelliKeys as an input device, and now does much of his writing using a regular keyboard with a keyguard (a plastic keyboard overlay with holes over each key to prevent the accidental pressing of more than one key at a time).

At five, Anthony Notte is one of the most computer-savvy kids at school.

Technology is an equalizer for Anthony. He might not be very good at stacking blocks, but when he uses the computer, he feels confident and successful. And since few kindergarten children have access to a computer, Anthony is also an object of fascination and, perhaps, a small amount of envy among his classmates. **EP**

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Circle #42

Environmental Control

by Naomi Angoff Chedd

Most of us perform routine tasks day after day without ever realizing how much control we actually have over our environments and our lives.

For children with disabilities, especially significant physical limitations, controlling the environment has been difficult at best, sometimes impossible. For some kids, just turning on a bedside lamp can present a major challenge. Over the past dozen years, however, a new and exciting field called environmental control (EC) has started to allow people with physical and/or cognitive disabilities to lead more independent lives. As Steve Tello, Director of Technology, Training and Assessments at Seaside Education Associates in Weston, Massachusetts, remarks, "If you can operate a switch, you can control almost anything."

With the Eye Slaved Pointing System, users can control icons on a computer screen through eye gaze. (Photo courtesy of ISCAN, Inc., Cambridge, MA)

What's new in EC?

All of us, with or without disabilities, use environmental control devices every day. Who doesn't have a remote to change channels on the television set? EC has been around for a long time; it's just getting more sophisticated.

Many EC companies are now designing products specifically for people with disabilities. These new devices and adaptations can allow almost everyone to use the telephone, answering machine, TV, VCR, stereo and most other appliances that can be operated by a switch or button. EC devices range from plate switches that require a light touch but not great strength, to sip-and-puff headsets, in which a switch is connected to a straw so the user can operate the switch by breathing into the straw. And some EC systems can be operated by eye gaze alone.

Some environmental control units (ECUs) are stand-alone, remote-control boxes, while others require connection to a personal computer. X-10 compatible remote controllers are among the most popular type of stand-alone devices. X-10 receiver modules, through which the remote controllers send signals to appliances, can be plugged into any AC outlet programmed to provide on-off control of any appliance—including lights, heat and air conditioning, audio and video equipment, doors, computers and many kitchen appliances. All electric systems in this country are compatible with X-10 receiver modules, thus many ECUs use the "X-10 protocol."

Other stand-alone EC devices can control televisions, VCRs and stereo equipment. For example, a channel scanner—the small box that allows viewers to "surf" through channels on a television set—can be connected to any type of switch to provide control of the both the television set and the VCR. Voice-controlled VCR programmers, which start, stop, rewind, pause and fast-forward in response to a voice command, are also on the market. In fact, virtually anything that can be done with a button can be done with a voice speaking words, or consistent, close approximations of words.

Teenagers with physical disabilities may be especially interested in new options for using the telephone. Voice-activated speaker phones automatically answer, dial and store numbers, and disconnect when the caller hangs up; some even work with call-waiting. Many long-distance companies sell specialized equipment. And more than 30 states administer adaptive telecommunications equipment distribution programs that distribute free or low-cost telephone equipment to children and adults with disabilities. Available devices include big-button and hand-free phones, TTYs (teletypewriters with typewriter-like keyboards and view screens that, when connected to the phone, allow users to communicate by typing and reading) and light signalers, which alert someone with a hearing impairment to the ring of a telephone.

EC can also provide security. Many home protection systems work with phones; when the system is triggered, the phone automatically dials the police. Detection sensors protect doors and windows, reporting intrusions electronically to an emergency response service. Some systems also control thermostats, detect leaks or frozen pipes and turn house lights off or on at certain times. Parents whose children spend time at home alone or face frequent medical emergencies may find these systems particularly useful.

This sip-and-puff switch can be mounted on a wheelchair and used to operate a remote control device. (Photo courtesy of Prentke Romich Co., Wooster, OH)

When to adapt

Even very young children can benefit from EC devices. Nancy Steele, Director of Rehabilitation Services at the Massachusetts Easter Seals Society, suggests that parents add EC devices to their home "whenever a child is developmentally ready to explore the environment." Steele points out that one of the simplest environmental controls is the switch-adapted toy, which can be used

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by children as young as 12 months. But Steele also cautions parents not to *overwhelm* children with gizmos or gadgets.

Howard Shane, Director of the Communication Enhancement Center at Children's Hospital in Boston, emphasizes the importance of teaching very young children with physical disabilities that their actions can have an effect on their environment. To help children grasp this concept as early as possible, Shane suggests that parents "help their children explore and control their surroundings. Get them to turn the lights off and on, control the TV and VCR—everything they would do i. they were able to crawl or walk."

You may want to start with a simple light switch, then add a switch that will operate small appliances. With a little help and know-how, you can purchase parts at a consumer electronics store and assemble a functional EC system without spending too much money. As ECUs become more popular, devices and systems will become more readily available, and prices will likely drop.

Who benefits?

Everyone benefits from EC. Children with disabilities can gain more independence and greater self-esteem. Family members, teachers, schoolmates and people in the community will perceive children with disabilities as more capable. Because EC increases freedom and mobility, it allows children to participate in more activities and contribute more fully to school and community life. Ultimately, EC can expand each child's educational, social and career opportunities. **EP**

Naomi Angoff Chedd is a member of the Exceptional Parent *editorial staff.*

How do I find out about EC?

- Ask an occupational therapist (OT) who has experience with adaptive equipment and knows your child's needs and capabilities.
- Ask an OT or augmentative communication specialist for the names of EC vendors. Most EC vendors are happy to talk informally about your specific needs and what's generally available, as well as discuss their own products.
- If you have access to a computer on-line service, spend some time browsing. You'll find a great deal of information on environmental control and related topics—product reviews, conference schedules and possible funding sources.
- Attend an assistive technology or home automation conference where many companies exhibit and demonstrate their products. These conferences, which function like trade shows, are good places to get a great deal of information in an afternoon. You can find out about conferences in your area by consulting computer on-line service announcements, occupational therapists or any other professionals in the assistive technology or augmentative communication fields.
- Call or write to RESNA, an interdisciplinary association for the advancement of rehabilitation and assistive technologies, at 1700 N. Moore St., Suite 1540, Arlington, VA 22209-1903; (703) 524-6686 (voice), (703) 524-6630 (TTY). RESNA can direct you to the federally-funded Tech Act project in your state, which can provide you with technical assistance, advice on funding sources and related information.

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Circle #171

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TECHNOLOGY

Exploring Telecommunications

by Abby Albrecht

I first went on-line during my sophomore year of high school. My dad had just installed America Online (AOL) software on the family's home computer, allowing us to use our computer and modem to connect to this commercial on-line service. I asked if I could try it out for a few minutes. The next thing I knew, three hours had passed, and I'd made a dozen new friends.

The high school party scene was never my thing. I wasn't into drinking, and my electric wheelchair did not fit into any of my friends' cars. So, instead of going out, I spent my time exploring everything the on-line world had to offer. I checked out the national, commercial on-line services—like AOL, Prodigy and CompuServe. I also joined several local bulletin board systems (BBSs). These small, non-commercial on-line services are often run from an individual's home and typically serve users for whom the BBS telephone number is a local call.

Friendships

I developed many on-line friendships with people I "met" in chat rooms or on message boards. In a chat room, you can have "real-time" discussions with others by typing messages and waiting for responses. Message boards work like bulletin boards in an office; people publicly "post" short questions or comments that can be read by anyone who visits the board, and any reader can respond by posting his or her own message. On-line relationships typically begin with exchanges in these public forums, then graduate to the exchange of private messages through electronic mail (or "e-mail").

I developed on-line friendships that were based on my personality and character, and had nothing to do with my looks or style. In fact, many of my on-line friends still don't know I have a disability. It has never come up because it just doesn't matter.

Abby Albrecht, 19, a junior at the University of Southern California, says she has made more than 100 on-line friends from all over the world.

Within a few months after my first on-line forays, my off-line friendships also began to blossom. Because of the acceptance I had experienced on-line, I began to open up to the flesh-and-blood people I saw everyday. I had gone to class with some of these kids for years, but had never made the effort to get to know them.

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Telecommunications Leads to Independence

The world of telecommunications is exciting. I've been on-line for more than a year, but I'm still thrilled to sign on to America Online (AOL) and hear the computerized voice say "You've got mail!"

Telecommunications technology allows me to do what every other teenager does—talk on the phone. And the best thing about it is that there's no one looking over my shoulder! For the first time in my life, I feel totally independent.

I use e-mail to talk to all kinds of people on the Internet. I talk to my Uncle Eric, who works at Oracle, a large software company. He helps me with my math homework.

I also send e-mail to my best friend, Neetu. Neetu just went away to college so I don't see her very often anymore. This is especially difficult because I used to see her every day. I miss the times we had together. It helps that I can write my thoughts and feelings to her through e-mail.

There's lots of stuff waiting to be explored on-line. Once, I almost used an on-line service to order flowers for my sister, but Mom caught me in the act! Sometimes, I visit "chat rooms" on AOL to talk to other people who are on-line at the same time as me. Telecommunications even helps me with my homework. I can use an on-line encyclopedia and download all kinds of information. When my homework is finished, I can even download games to play off-line on my personal computer.

More recently, I discovered how to use my modem to access the telephone relay service for people who are deaf or have other disabilities. Before I discovered the relay, I needed help to make phone calls. Someone had to dial the number for me and turn on the speakerphone. Then I would use my augmentative communication device to have a phone conversation.

With the relay service, however, I can use the phone all by myself. Here's how it works: I use my computer and modem to dial the relay service. A relay agent answers and places the call for me, then reads what I type to the person I have called. When that person replies, the agent types their words and I read it on my computer monitor. It is neat having private conversations; it's the first time in my life I've had secrets.

—*Vanessa Coveau*

Vanessa Coveau, 16, is a sophomore at Mission San Jose High School in Fremont, California.

Vanessa and her mother, Lucy, are in the process of developing a directory of teenagers with disabilities who would like to communicate with each other by e-mail. Those who wish to be included in the directory should e-mail the following information to vansc@aol.com: name, age, city, state, e-mail address and anything else you would like to say about yourself. You will receive the current directory by return e-mail.

TECHNOLOGY

Getting Started

To the uninitiated, cyberspace may seem like an intimidating place. In truth, however, you need only four components to start exploring the on-line universe: a phone line, a personal computer, a modem and a subscription to an on-line service. For most people, a commercial on-line service like America Online (AOL), Prodigy, CompuServe or eWorld is the best place to start. Subscribers to one of these services receive user-friendly software through which to access the service. And if you have any problems making that initial connection, you can quickly find help by placing a toll-free phone call to the service's customer-support helpline.

Each commercial on-line service offers its members message boards, chat rooms and other special features such as up-to-the-minute news and weather reports and on-line encyclopedias. The commercial services also provide a "gateway" to the Internet, which is a world-wide network of interconnected computer networks. Subscribers to a commercial on-line service like AOL have the capability to send electronic mail to other AOL subscribers. But because AOL (like other commercial services) is connected to the Internet, they can also send e-mail to anyone who has Internet access through any other service.

Outside of the commercial on-line services, many people obtain Internet access through an Internet-connected computer network at their universities or places of work. Others get Internet access through local BBSs (electronic bulletin board services), community-sponsored computer networks (called "Freenets") or commercial Internet providers that charge a monthly fee and provide a local access number.

What's out there?

• *E-mail:* The capacity for users to send and receive electronic mail is often cited as the most important benefit of online communication. E-mail refers to private messages that can be written and sent instantaneously to other computer users. And unlike conventional postal services—disparagingly referred to as "snail mail"—e-mail can be sent and received at any time of the day or night.

• *Mailing lists:* An individual can use his or her e-mail address to "subscribe" to one or more of the thousands of available e-mail discussion groups, commonly referred to as mailing lists. Mailing lists allow subscribers to participate in ongoing discussions on almost every topic imaginable. Any new message or response sent to a mailing list is distributed to every subscriber.

• *Newsgroups:* Internet newsgroups work like message boards on the on-line commercial services. More than 5,000 newsgroups focus on a variety of topics. Each newsgroup stores messages on a computer in a central location, and users read and reply to these messages from their own computers.

• *World Wide Web:* The World Wide Web provides a way to display information on the Internet. The Web is made up of interconnected "pages" (sometimes called "sites"), each containing textual and graphical information on a specific topic. To access the Web and move from page to page, users need software known as a "Web browser." Most of the commercial on-line services now offer their own Web browser software, thus providing their users with a gateway to this rapidly growing part of the Internet.

Web browser software allows you find information on any subject with the click of a mouse button. There is no need to type complicated commands. When the browser finds the location you want, it downloads (receives) the information from the computer at that site and displays it on your computer.

Take the plunge!

Chances are, some of the people you know are already on-line. Talk to your friends and find out about the on-line services they're using. Then go ahead and give it a try!

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My new friends, on- and off-line, all had one thing in common—they didn't care that I used a wheelchair; they liked me for me.

Creating communities

After graduating from high school, I began my college studies at the University of Southern California. Unfortunately, my family's computer equipment stayed home. When I could afford to buy a modem during my sophmore year, I was able to get reacquainted with AOL and the local BBSs. I was also able to get a free Internet account through the university. The Internet (an electronic network of hundreds of thousands of interconnected networks) did not have the fancy graphics and user-friendly interface of the commerical on-line services, but I didn't care. I was anxious to explore this new dimension of cyberspace.

Around that time, a magazine I was reading suggested checking out Internet "newsgroups" about the "X-Files," one of my favorite television shows. When I went on-line looking for these newsgroups, I also discovered e-mail discussion groups, or "mailing lists." There are thousands of these lists on the Internet. Each brings together people with a common interest—everything from a favorite television series to a college alumni association to a specific disability. For example, one of the five groups I joined revolves around David Duchovny, star of "The X-Files." It was strange and exhilerating to "talk" with people from all over the country who shared my interests and tastes.

Although members of these groups come together because of a common interest in a specific topic, I soon discovered that conversations veer into other topics as well. The anonymity of on-line conversation may make people feel more comfortable talking about subjects they would never think of discussing with off-line friends.

Karen Knight, one of my on-line friends from Duchovny-L (the "L" identifies it as a mailing list), agrees. "The gang at Duchovny-L has become my family," she says. "We talk about many things. We have rational discussions about religion, abortion, sexual orientation and a number of other issues."

On-line communities also offer people with disabilities a way to make connections with others who are dealing with similar challenges. On-line disability forums offer opportunities to share thoughts and ideas. Topics can range from personal care attendants to dating. As Rachel Stewart, one of my old friends from muscular dystrophy camp, explains, "I can't talk to my [able-bodied] friends about everything. They don't understand some of the things I've been through. But on AOL, I can talk with other people who are disabled and know what I deal with every day."

Warm fudge and soda

Last summer, "X-Files" fans who had been "meeting" on AOL for about a year, decided to take a bold step out of anonymity. Together, we planned an "AOL 'X-Files' Convention" in Las Vegas, the first of what we hoped would become an annual event. Finally, everyone who had been writing to each other for the last year would have the chance to see their friends, face-to-face.

Once we were relaxed enough to speak as honestly in person as we do on-line, everyone admitted to an initial fear of attending the convention—*what if they don't like me in person?* But our on-line relationships had already gone beyond the superficial; looks still didn't matter. One of my friends and I spent several hours bonding over warm fudge and soda—something we could never do through a modem.

A valuable tool

On-line services are definitely addictive. Everyone learns moderation after a while. But in the beginning, when I was trying to learn everything I could, my AOL bill was huge.

Still, it's impossible to put a price tag on what my on-line travels have given me. If I had not learned to open up to complete strangers in cyberspace, I never would have had the courage to go out and find friends off-line. And it was on-line communication that first sparked my interest in writing, an interest that has led me to pursue a career in public relations. Telecommunications is a valuable tool—a tool that has helped me learn more about who I am and who I can be. **EP**

Fourteen-year-old Rachel Stewart (left) enjoys frequent e-mail communications with her friend, Annie Wilson (right), 13, who lives an hour away, on the other side of the San Francisco Bay. Both girls have spinal muscular atrophy.

Abby Albrecht, 19, is a junior at the University of Southern California, where she is majoring in public relations. She is a staff writer and a book editor for the student newspaper, THE DAILY TROJAN. She also works in the university's Office for Students with Disabilities, where she helps other students with disabilities adjust to life on campus.

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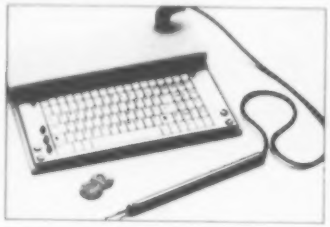

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GUEST EDITORIAL

TECHNOLOGY

Imagine the Future

It's about concepts, not things!

by Alan Brightman

In the field of disabilities, discussions about the future of high technology seem to invariably center around *things*. New gadgets, faster gadgets, gadgets that do the wondrous and gadgets that do the mundane. Hardware things. Software things. Always, it seems, talk about the future is talk about some *thing*.

Which, in my opinion, misses what the future is really going to be about.

When I think about tomorrow and next year and five years from now, what excites me more than anything else is the idea of connectedness, no longer being isolated, making choices to participate in virtually anything.

Connectedness is a concept, not a thing. And yet, it's what I believe the future of high technology will offer to everyone concerned with kids and adults with disabilities, with their parents and family members, and with the helping professions that serve them all.

In a recent advertisement, AT&T used the phrase "long-distance togetherness." That phrase beautifully describes the future I see. Telecommunications, online services, the Internet, the "information superhighway"—you've surely heard of these things. But have you tried them yet? Have you started to experience the future?

It's time. The future is just about here.

We are experiencing the benefits of this future even today. With telecommunications, parents are consulting and commiserating with other parents in faraway states, even other countries—all for the price of a local phone call. Kids are chatting with other kids—hundreds at a time or one-on-one—sending the sound of laughter across standard phone lines. Researchers are scanning library collections in seconds, no matter where the library is located.

None of us knows where the information highway will lead. But that shouldn't stop us from beginning our individual journeys. It's okay to get lost (and you will). Like any wanderer, you will stumble upon the unexpected. And you'll be amazed by what you'll find.

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My Television Classroom

While undergoing six months of chemotherapy, Joe "attended" school by television monitor in his dad's home office, where Bell Atlantic had installed an ISDN connection.

My name is Joseph Zlotek, but everyone calls me Joe. I am 10 years old. I live with my mom, dad and baby sister, Sarah. I go to Cedar Creek Elementary School in Forked River, New Jersey.

I like going to school. But last year, I couldn't go to school for five months. I had to have a tutor come to my house. I really wanted to go to school instead of having a tutor, but because of chemotherapy, I couldn't.

Then the phone company (Bell Atlantic, to be exact) called my mom. They told us we could have a special telephone hookup that would let me be part of my class from home. The telephone company people came and hooked it up in my Dad's home office.

It was really cool. It was called ISDN. ISDN stands for Integrated Services Digital Network. ISDN let me see and hear the teacher and the kids at school on a TV at home. They had a TV in the classroom, so they could see and hear me, too. I could even read the same book as the class because of a "document camera" that sat beside the TV. The camera looked kind of like an overhead projector.

One day, my whole TV screen went black. I could still hear everybody at school, but I couldn't see them. Fortunately, I was able to fix the problem myself by using the small control board. It wasn't a serious problem. It would have been more serious if I couldn't hear anything through the TV. Then we would have had to call Bell Atlantic. They told us they would come any time I needed them. But that never happened.

The document camera allowed Joe to look at the same books and worksheets as his class at school.

It was great using ISDN to see everybody at school. It was great to be in class, except I couldn't go outside to recess. So I asked my teacher, Mrs. Schmitt, if a few of my friends could stay in from recess. She agreed, and we were able to use ISDN to talk and play during recess.

—Joe Zlotek

In January 1994, Joe Zlotek was diagnosed with a germ-cell tumor in his throat. He had surgery to remove the tumor, followed by six months of chemotherapy. Now 10, Joe is in the fourth grade at Cedar Creek Elementary School in Forked River, New Jersey. Doctors monitor his condition with monthly blood tests; to date, he remains cancer-free.

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Continued from page 41

In this connected future, we'll learn to expect the unexpected and to attain the previously unattainable.

Want to attend that all important conference, but just can't afford to hop on a plane and be away for three days? No problem: connect to the conference from your kitchen table. Listen, watch, participate—at your convenience, with just a local phone call.

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We have always characterized computers as the technology of independence. We've represented them that way because children and adults with disabilities viewed these devices in just these terms.

In the future, those terms will change. The technology, as a set of devices, will be no more exciting than a rotary phone. But thanks to advances in telecommunications, what we'll be able to do with that technology will bring about an unprecedented democratization of individual opportunity.

At the moment, we can only imagine these kinds of dreams and ideas. Your family should be part of that imagining. You *need* to be part of that imagining.

After all, it's not our future. It's yours.

And if you don't start dreaming about it, and making it happen, who will? **EP**

Alan Brightman is the manager of Apple Computer's Worldwide Disability Solutions Group, which he founded in 1985.

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The Alliance for Technology Access (ATA) began in 1987 as a joint project of a grassroots organization—Disabled Children's Computer Group—and a major corporation—Apple Computer.

From this small group of parents, consumers and professionals, the ATA has grown into one of the nation's largest resources to help adults and children with disabilities gain access to the benefits of adaptive technology.

The ATA's most important means of promoting technology access may be its nationwide network of community-based assistive technology resource centers. ATA centers work with a wide variety of individuals and organizations and have no eligibility criteria for determining who may receive services. Most centers provide hands-on consultations and product demonstrations, make recommendations and referrals, and present workshops on technology use.

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Center for Accessible Technology
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(808) 523-5548 (fax)
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Technical Aids & Assistance for Persons with Disabilities (TAAD) Center
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NEW JERSEY

Center for Enabling Technology
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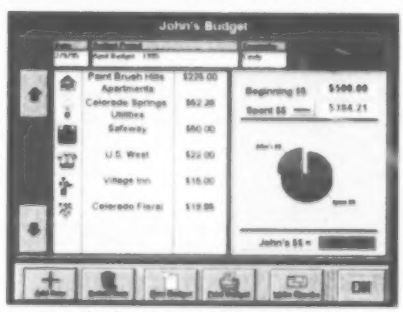

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Circle #279

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Virgin Islands Resource Center for the Disabled
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The TECH TOTS Project: Technology belongs to everyone

by Kathleen Gradel

Sarah, a two-year-old who cannot crawl or walk, is known in her neighborhood as "the kid with her own car." She gets around in a yellow, battery-operated jeep, by pressing a switch on the steering wheel, instead of the "accelerator" pedal. Sarah's mom laughingly says, "I think she drives just like her father!"

Sarah found her car at a TECH TOTS Library, a project of United Cerebral Palsy Associations, Inc. (UCPA). These libraries give families of preschoolers with disabilities an easy way to try out different types of technology—everything from toys and computers to mobility equipment.

Today, there are 19 TECH TOTS libraries nationwide, reaching over 1,000 families of children with disabilities each year. Membership costs up to $25 per year and varies from site to site; sliding scale options and alternative methods of payment, such as volunteering time, are available.

There are three ingredients to the TECH TOTS "recipe." First, families are in charge. TECH TOTS libraries are run by parent coordinators—family members who already know the "ins and outs" of technology. Coordinators do everything from teaching other families and youngsters to use equipment, to organizing and maintaining all equipment, to recruiting library members. A second ingredient is the equipment itself: libraries stock the full range of computers, toys, adaptive switches, mobility equipment and more. The most vital ingredient is the belief and practice that technology belongs to everyone. This means that families borrow equipment, just as they would check out books, tapes and records at the local public library, or rent a video game. TECH TOTS is based firmly on the philosophy that technology should be touched, bumped, fondled and bruised by kids, parents, brothers, sisters, grandparents and pals.

TECH TOTS believes in families being active partners in decision-making about technology—and making technology "happen" for their sons and daughters. Through TECH TOTS, families report the following: they make informed decisions—and exercise choices—about what meets their children's needs, what works and what doesn't; they are in charge of fun and learning for their children—not in the back seat; they don't wait for someone else to introduce technology to them; they get comfortable with equipment and decide what works. Most important, we hear that kids and families get technology's enabling "bang"—that they become "doers" rather than "watchers."

For more information, write, call or e-mail United Cerebral Palsy Associations, Program Services Dept., 1660 "L" St. NW, Ste. 700, Washington, DC 20036; (800) 872-5827, (202) 775-0406, (202) 776-0414 (fax); ucpainc@aol.com (e-mail). UCPA can help you:

- Find a TECH TOTS Library in your area;
- Order materials—or get training and assistance—to start your own TECH TOTS Library;
- Donate equipment to the TECH TOTS network; or
- Sponsor a family's membership in a local library.

Kathleen Gradel is Director of the Program Services Department at United Cerebral Palsy Associations, Inc.

VIRGINIA

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Circle #14

"Special Ed" Deserves Special Emphasis

by Rep. Randy "Duke" Cunningham

Greg is a young attorney. He does some work for a Washington-based association. California Governor Pete Wilson recently named him to a state advisory panel.

This might be the story of just another ordinary up-and-comer, except that Greg was diagnosed with cerebral palsy in infancy. His lack of muscle control slows his speech; he needs a motorized wheelchair to get around and uses a computer to write.

Greg's success would not have been possible without the Individuals with Disabilities Education Act, or IDEA, which mandated and financially supported his education. In generations past, Greg probably would have been institutionalized.

Fulfilling our moral commitment

IDEA helps fulfill our nation's moral commitment to educating America's children with disabilities. Education transforms individuals who were once thought to be helpless, into productive, working, taxpaying citizens.

The cost of providing "special ed" and other services to five million American children with disabilities is considerable. Congress contributes about $3.3 billion to an enterprise that costs up to $50 billion a year. But this expenditure makes excellent fiscal sense. Our investment of time and resources into education for these students spares the financial cost of lifetime institutionalization, which might cost from $15,000 to 80,000 a year for each child. It also preserves the important contributions people with disabilities make to society.

This law is explicitly built upon constitutional rights and protections. Applying our 14th Amendment right to "equal protection under the law," it ensures that children with disabilities receive a "free, appropriate, public education" in the "least restrictive environment" based on an "individualized education program" (IEP) that is agreed to and regularly reviewed by the child's parents and school. IDEA also authorizes federal funding to help states accomplish this task.

A history of exclusion

Twenty years ago, children with disabilities inhabited American society's dark fringe. Very few states provided any type of "special ed" as we know it today. More commonly, schools simply excluded students with special needs from the classroom.

In the late 1960s, parents of children with disabilities began taking their outrage to court. Two cases, *Pennsylvania Association of Retarded Citizens v. Commonwealth of Pennsylvania* and *Mills v. the Board of Education of the District of Columbia*, reached the federal courts.

Pennsylvania Association of Retarded Citizens challenged that state's out-dated school code, which prescribed housing people with mental retardation in institutions because Plato's *Republic* recommended that "the offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should be." Children with mental retardation who were "disruptive" in class, not performing at grade level, or deemed "uneducable" were sent home for good.

Things were even worse in our nation's capital. Children with disabilities roamed the streets of Washington, D.C.

The courts ruled on both cases in the early 1970s, stating that such cavalier treatment of children with disabilities violated the children's constitutional right to equal protection under the law. These rulings, followed by a growing number of sometimes-conflicting cases arising in other federal district courts, motivated Congress in 1975 to enact IDEA's precursor, the Education for All Handicapped Children Act (Public Law 94-142).

During the last 20 years, P.L. 94-142 and IDEA have transformed the lives of children with disabilities in America. Once these children were neglected as a matter of practice. Today, they are educated to take part in the American dream. Many, like Greg in California, do just that.

Common-sense themes

The IDEA legislation is scheduled to be reauthorized this year. The House of Representatives Subcommittee on Early Childhood, Youth and Families, which I chair, has held hearings on the reauthorization. Our primary goal is to renew and improve IDEA to better serve children with disabilities and their families. The renewal of this law centers on five common-sense themes:

- *Quality results for all students:* Schools should be accountable for all of their students, including those who have disabilities. The IEP for each student with a disability should be a working document focusing on educational results, not a list of perfunctory services and procedures. Students with disabilities should be expected, to the maximum extent possible, to meet the same high expectations and challenging standards that have been established for all students.
- *Strengthening the family's role:* Parents of children with disabilities have enough challenges without adding arrogant "educrats" to their burden. When decisions are being made about their children's education, parents must be informed of their options and rights in clear, practical language. Parents must be full partners with the decision-making team, from evaluation through placement.
- *"Win-win" dispute resolution:* For most families, the process of determining IEPs for children with disabilities works fairly well. But when things go wrong, legal costs can skyrocket and drain resources away from the education of children. Instead of forcing families and schools into an adversarial legal system, we will encourage states to have a mediation process that will offer parents ways to develop educational solutions in which everyone "wins."
- *Teacher preparation, during college and beyond:* Children with disabilities vary as widely as children without disabilities. Classroom teachers, both in regular education and special education, must have the information and resources they need to do their jobs right.
- *Useful research:* Parents and teachers lack solid research results to guide them on the best educational course for chil-

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dren with disabilities. The renewal of IDEA should lead to building a strong research base that can improve education for children with disabilities.

Discipline, inclusion and funding

Most people can agree on these five issues. The areas of greatest division, where Republicans and Democrats are working hardest to build consensus, have to do with discipline, inclusion and funding.

The issue of discipline is particularly difficult because the law gives children with disabilities certain rights and privileges other children do not have. This is a product of the (until recently) sad history of schools' failure to educate children with disabilities. In the past, for example, "typical" children who disrupted a class by chewing gum may have been disciplined with detention, while children with disabilities who "disrupted" class with twitching or slurred speech were kicked out for good. Fortunately, this is no longer the case, but it illustrates the difficulty of handling discipline for children with disabilities.

Currently, a child protected under IDEA can be suspended for up to 10 days for misbehavior. During those 10 days, the school works with the child's parents to determine the best course for addressing the problem.

The Jeffords Amendment to the Improving America's Schools Act allows a special-education student to be placed in an "interim, alternative placement" for up to 45 days if the child's violation involves a firearm. However, this extended "cooling-off" period is not enough. We cannot have children with disabilities bringing guns to school, then hiding from justice behind the noble goals of IDEA.

The law needs clear procedures for removing dangerous students from the classroom, with instructions for determining whether the behavior is related to a student's disability. If a child's misbehavior has nothing to do with his or her disability, schools should have the flexibility and authority to discipline as they see fit.

The second controversy has to do with "inclusion," the practice of incorporating children with disabilities into the regular classroom rather than segregating them in "special ed" classes. Children with disabilities can benefit from time spent in the regular classroom. Their classmates without disabilities can also benefit. However, some people argue that inclusion is difficult, inconvenient, costly, damaging to the education of students without disabilities and less than ideal for children with disabilities. In some cases, these concerns are justified. But the placement of a child with disabilities in a regular classroom is, and should continue to be, the product of careful cooperation among parents, teachers, and administrators though the development of a child's IEP. The ultimate goal of the IEP process for each student with a disability should be to find the educational setting which provides the best possible educational results—whether a regular classroom, a separate classroom or a combination of the two.

Funding will always be a challenge. When the law was written, Congress pledged to provide states with 40 percent of the funding needed to educate children with disabilities. Today, the federal contribution of $3.3 billion covers only about seven percent of these costs. It is difficult for public schools that are already strapped for funds, to provide costly services to children with disabilities. We will do our best to maintain funding for IDEA as we bring the federal budget into balance.

A chance at the American dream

It is my hope that we will continue the bipartisan consensus supporting the education of America's children with disabilities. Their chance at the American dream depends on our determination and hard work on their behalf, through prompt and thorough renewal of IDEA. **EP**

Representative Randy "Duke" Cunningham (R-CA) is the chairman of the Subcommittee on Early Childhood, Youth and Families of the House of Representatives Committee on Economic and Educational Opportunities. He is a former teacher and coach, and a retired U.S. Navy fighter pilot.

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Circle #110

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by Joanne & Stephanie Oppenheim

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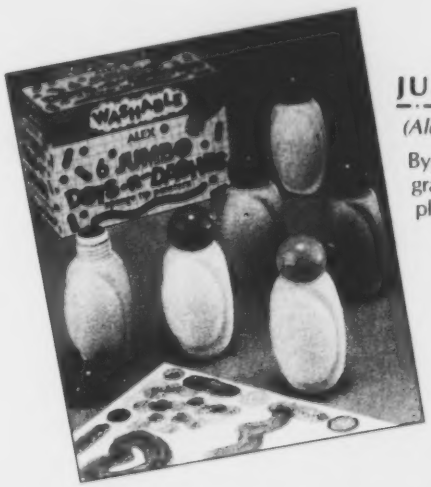
Art materials are more than fun. They motivate kids to develop dexterity and express feelings, and they provide a great deal of sensory feedback. Creative exploration—without lots of rights, wrongs or rules—gives kids a wonderful sense of "can-do" power.

These art materials require little or no adaptation for children with disabilities. Most can be found in any toy store. Following the name of each item, in parentheses, is its manufacturer, the recommended retail price and a customer service number that may be used for ordering or for more information. Following the description of some items are suggested adaptations or activity tips.



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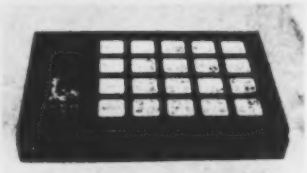
Adaptation idea: *Place a piece of blank paper over one of the drawing sheets so child can draw original art as he or she activates a musical accompaniment.*

Activity tip: *Use the premade drawing sheets for an "I Spy" game. Have child find and touch the animal that goes "moo" or "oink" in the picture.*

These products were reviewed by the Oppenheim Toy Portfolio, an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes THE BEST TOYS, BOOKS & VIDEOS FOR KIDS and also publishes a quarterly newsletter. Both publications include learning activity ideas and ways to adapt ordinary products for kids with special needs. To subscribe to the newsletter, send $12 to The Oppenheim Toy Portfolio, 40 East 9th, Suite 14m, New York, NY 10003.



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Circle #220

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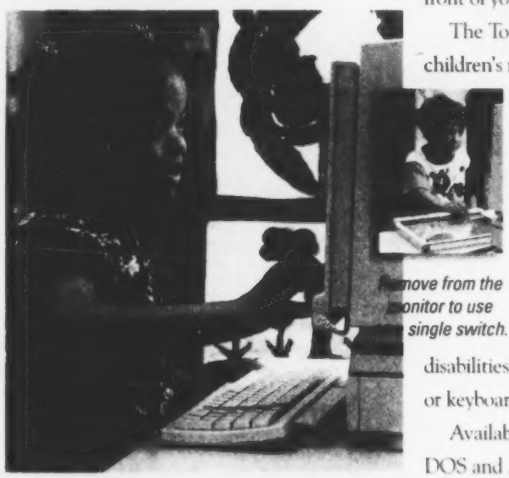

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Circle #109

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Can Medication Change Behavior?

Since the age of six, Andy Ayres had shown the extreme distractibility and restlessness associated with hyperactivity. Andy, who has Down syndrome, constantly ran through the house turning knobs and picking up objects. He would often awaken at 2 a.m. By the time Andy turned eight, his parents, Carole and Carter, began to notice further disturbing and dangerous behaviors.*

"He was riding his bike directly into traffic," said Carter. "Other times, we'd find him sitting in the road in the middle of the night."

Andy was diagnosed with a bipolar disorder—a mental illness also known as manic-depressive disorder—involving alternating phases of excessive excitement and activity (mania) and persistent, profound sadness and feelings of worthlessness (depression).

"We thought Down syndrome was the only challenge we had to deal with," said Carter. "We weren't expecting Andy to have a mental health problem..."

Research has shown that certain behavior patterns can be directly related to specific diagnostic conditions. (See, for example, "Beyond Labels" by Karen Levine, Ph.D., October 1995.) But Andy Ayres' troubling behaviors were not typical of children with Down syndrome; rather, these behaviors turned out to be symptoms of bipolar disorder, an unrelated condition. This diagnosis led to Andy's treatment with the same psychoactive medications that may often help other individuals with the same type of mental illness—individuals who do not have Down syndrome.

Moving away from blame

It is not uncommon for parents or professionals to attribute a child's inappropriate or unusual behaviors or feelings to factors related to his or her disability.

* *Andy's parents, Carol and Carter Ayres told Andy's story in* EXCEPTIONAL PARENT's *April/May 1993 issue, in an article entitled "Tough Choice." We appreciate their willingness to share more of their family's experiences in this article.*

About this article:

Recent research has demonstrated that the body and the "mind" are not two separate systems; rather, there are complex interrelationships between the two. Many troubling behaviors and/or emotions may be caused, at least partially, by physiological processes. These processes, in turn, may be affected by life experiences.

Much remains to be learned about these processes, and misunderstandings still occur. One source of misunderstanding is the myth that individuals are in complete, conscious control of their feelings and behaviors—that all behavior is planned, and that individuals are aware of their specific motives for behavior. In truth, the causes of behaviors and feelings are extremely complex, and disagreements about the source of certain behaviors and emotions exist even among mental health specialists.

Terminology is often another source of misunderstanding. For example, terms such as "emotionally disturbed," "psychological problems" and "mental illness" may be used to describe children, with or without other disabilities, who have serious problems in everyday life—problems controlling behavior, making friends or feeling good about themselves. Any given term, however, may not mean the same thing to everyone who uses it.

This article focuses on the use of medications to treat troubling behaviors and/or feelings in children with disabilities. It does not address controversies about definitions and labels, nor the specific qualifications and skills of various types of mental health professionals. Nor does the article discuss the misuse of medications that has sometimes occured in institutional settings where appropriate therapeutic or educational programs are unavailable.

Some professionals blame all of a child's "bad" behaviors on parental reactions to the child's disability.

Similarly, in the past, when children with mental retardation behaved in troubling ways, professionals often believed the behavior to be related to the child's intellectual limitations or dismissed it as an attention-getting device. Some people believed that individuals with mental retardation and/or communication difficulties lacked the intellectual or emotional abilty to experience mental illnesses. Perhaps most damaging, many professionals once believed autism to be a mental illness caused by inappropriate parenting.

Andy Ayres, 7, enjoys an affectionate moment with his father and grandmother. "We thought Down syndrome was the only challenge we had to deal with," says his dad. "We weren't expecting Andy to have a mental health problem."

Much has changed and continues to change in our understanding of the causes of troubling behaviors or emotions in children and adults. We now know that children or adults with mental retardation and individuals who are unable to communicate verbally can have emotional problems or mental illnesses. And autism is now considered to be a developmental disability that is present at birth (see "Medication and Autism," page 52).

The role of stress

In stressful circumstances, all individuals may experience less self-control and may behave in less mature ways. Individuals with mental retardation and/or communication difficulties may have particular difficulty coping with stress. For example, a child who is unable to express his or her feelings and needs with understandable speech may become increasingly frustrated and angry.

In fact, individuals with mental retardation and/or communication difficulties may be more susceptible to certain emotional and behavioral disorders than other individuals. For example, some children with disabilities may find school particularly stressful. Some children with mild to moderate mental retardation who are placed in regular classrooms may recognize that they are intellectually

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At 10, Andy entered the psychiatric unit of a local hospital for treatment of a bipolar disorder. Hospital staffers snapped this identification photo on the night he was admitted.

behind others of the same age and may experience feelings of failure, particularly if they are not provided with appropriate supports. Others may suffer low self-esteem if they are placed in a specialized educational setting they feel is beneath their capabilities.

Challenges in assessment

When children, with or without disabilities, behave in troubling ways, a comprehensive assessment by a mental health team can be helpful.

While every child has ups and downs, intervention may be needed if something that looks totally out of character is observed—for example, if a child who is usually well-behaved suddenly becomes hyperactive and elated, or if a typically happy child appears depressed and morose. A marked change in sleep patterns may also reflect an underlying disorder.

Mental illness is not always the correct explanation for troubling behavior, however. A first step is to determine whether or not a specific behavior is appropriate for the child's level of intellectual and emotional development. For example, an adolescent who regularly talks out loud to himself might be considered "odd." However, such behavior may be "appropriate" for a 14-year-old with mild to moderate mental retardation. Without considering the child's developmental level, the behavior might incorrectly suggest a psychosis, such as schizophrenia.

Steps toward accurate diagnosis

To obtain an accurate diagnosis, professionals and parents should first try to identify the source(s) of the troubling behavior(s). This process includes an investigation of possible physical origins or links to a specific developmental disability. For example, symptoms of hypothyroidism—a deficiency in the functioning of the thyroid gland—can be mistakenly interpreted as depression; both have similar clinical pictures, including chronic sleepiness and lack of energy.

It is also important that the clinical team—including parents, educators and mental health professionals—examine the child's day-to-day environment. Since children participate in different activities in different settings and are supervised by a variety of caregivers, the team can try to determine whether inappropriate behavior(s) are reactions to specific events, environments or individuals, or whether these behaviors result from an internal source that causes the behavior(s) in every environment. When the same behavioral difficulties occur in each setting, the source is probably within the child and can be considered a psychological problem or mental illness.

Biochemical and genetic clues

Current research indicates that many mental illnesses are related to an imbalance of neurotransmitters—chemical messengers in the brain. For example, studies show that low levels of the neurotransmitters serotonin and norepinephrine may contribute to depression.

Family histories can reveal a genetic vulnerability to certain mental illnesses. For example, unipolar depression—depression without a manic phase—is far more common in children whose biological parents also had unipolar depression, even if those children were raised by adoptive parents. A genetic relationship can be found in manic-depressive (or bipolar) disorders as well. Andy Ayres' younger brother was subsequently diagnosed with a manic-depressive disorder, and there is a history of the disorder in the families of both parents.

Thirteen-year-old Andy (right) clowns around with younger brother Chris, 11, outside the residential school Andy now attends.

The significance of biological factors does not mean medications can "cure" mental illnesses in the same way an antibiotic might cure a disease like pneumonia. Experts stress that medications are most effective when used as part of a treatment program that may include behavior management (attempts to teach more appropriate behaviors through the systematic use of rewards) and/or psychotherapy (a form of treatment that involves play and/or discussions between a child and therapist to bring about a change in the child's feelings and behaviors).

Medication and assessment

A specific, diagnosable mental illness is not always clear even after a thorough clinical assessment. In those cases, diagnosis can be a process of elimination.

Trials with medication used to treat specific symptoms can sometimes help to clarify a diagnosis. For example, it can be difficult to determine whether depression is a unipolar depression or part of a bipolar (manic-depressive) condition. Treatment with anti-depressant medications can help clinicians make this distinction, because such medications can trigger manic behaviors when administered to an individual in the depressive phase of a bipolar disorder.

Common psychoactive medication

There are several broad categories of psychoactive (or "mind-affecting") medications. These medications should be prescribed only by physicians who are experienced in their use. Ideally, they should be prescribed by a psychiatrist (a physician with specialty training) who also has experience treating individuals with disabilities. Below, brand names are listed first; generic chemical names follow in parentheses.

•*Stimulant medications*, such as Dexedrine (dextroam-

continued on page 52

Medication and Autism

Although autism is characterized by a variety of unusual behaviors, it is considered a developmental disability rather than a mental illness, because it can be linked to a structural irregularity in the brain (approximately 25 percent of children with autism also have seizures). In addition, autism is usually diagnosed in infancy or early childhood, earlier than most mental illnesses.

Typical behaviors

Unusual behaviors typically seen in autism include:

• Inability to form normal intimate/social relationships: Infants or toddlers with autism often resist affection from or are indifferent to parents or caregivers. As they get older, most children with autism have difficulties related to social interaction. Some seem to desire friendships but are unable to initiate such relationships appropriately.

• Unusual relationship with objects: A child with autism may show either avoidance of or intense attraction toward particular objects, such as pieces of string, wheels on toy cars, rocks or paper clips. Some children with autism are extraordinarily fascinated with moving objects, such as fans.

• Repetitive or "stereotyped "behaviors: Children with autism may engage in repetitive, seemingly uncontrolled movements such as hair-pulling, arm-flapping, head-banging or continually repeating specific vocalizations (sounds or words). Some people consider these behaviors "tics" (involuntary, repetitive movement of a muscle or small muscle group).

Some children with autism engage in "obsessive-compulsive" behavior, turning everyday tasks into elaborate rituals that must be performed in a precise manner. For example, a child with autism may insist on taking exactly seven steps from his or her bed to the door.

Likewise, many children with autism become distressed when their environment is changed in any way. A child may become extremely upset if a particular stuffed animal is moved even slightly from its usual place.

• Hyperactivity: About half of all children with autism, especially children younger than eight, may be classified as hyperactive or as having attention deficit hyperactivity disorder (ADHD).

• Communication difficulties: Some children with autism are unable to speak, or if able, may use words in an unusual manner—perhaps repeating a single word over and over, often in situations when the word seems irrelevant. Often, children with autism also have considerable difficulty comprehending language.

Treatment with medication

Some typical behaviors of children and adults with autism appear similar to symptoms of mental illness seen in people who do not have autism or other developmental disabilities. As a result, some people have tried—with varying degrees of success—to decrease or eliminate some typical "autistic behaviors" with the same medications used to treat similar symptoms in individuals who are not autistic.

Research has shown that Trexan (naltrexone) increases sociability. Researchers at Children's Hospital of Pittsburgh have also reported that use of Trexan led to increased control of impulsivity and hyperactivity in younger children with autism. Prozac (fluoxetine) may also increase sociability, but like Trexan, is still considered an experimental treatment.

Some medications seem to hold promise for treating certain stereotyped behaviors. For example, Haldol (haloperidol) may help control the frequency and intensity of tics, and Naltrexone may reduce self-injurious behavior like hair-pulling and head-banging.

Many of the same medications used to treat "obsessive-compulsive" behavior in children and adults without disabilities—Prozac, Zoloft (sertraline) and Luvox (fluvoxamine maleate)—may also be used in children with autism. Unfortunately, these medications often do not work the same way for individuals with autism. At lower doses, they may appear somewhat effective. But increasing dosages to the same levels normally used in children without autism can produce adverse side effects, including irritability and aggressive behavior. With these relatively new medications, it is essential that the team be aware of the potential for toxic reations.

Hyperactivity in children with autism may be treated with the same stimulant medications used by children without autism. These include Ritalin, Dexedrine and Cylert. Children with autism, however, sometimes respond adversely to these medications; in some cases, their behavior deteriorates rather than improves.

Medication will be only one component of a team-based treatment plan for a child with autism. A specialized educational program and appropriate therapies will also be part of a comprehensive treatment program.

Some parents and professionals believe treatment with nutritional supplements can be effective in treating some autistic behaviors. However, the experts consulted for this article do not recommend this approach.

—*J.R.*

continued from page 51

phetamine sulfate), Ritalin (methylphenidate hydrochloride) or Cylert (pemoline), can be useful as part of the treatment for attention deficit hyperactivity disorder (ADHD).

•*Anti-depressants* may be used in the treatment of serious unipolar depression, school phobia (intense fear in young children of going to school), ADHD, and some serious anxiety disorders, ranging from vague, chronic unease to sudden panic attacks during which an individual may feel heart palpitations, choking sensations, dizziness and abdominal pain.

•*Antipsychotic medications*, such as Haldol (haloperidol), Stelazine (trifluoperazine) or Thorazine (chlorpromazine) may be prescribed for the individual with a psychosis—a break with reality that can involve hallucinations (perceiving sights and sounds that do not exist) or delusional thinking (believing in scenarios or identities that have no basis in reality, such as believing that one is God or Superman).

•*Lithium and Tegretol (carbamazepine)* may be helpful in treating bipolar disorders and minimizing future manic-depressive episodes.

•*Anti-anxiety medications* may be used short-term (from several days to approximately six months) for certain conditions associated with high anxiety. Their usefulness in children has not been well-studied, and their effects often seem to level off or fade with long-term, constant use.

Treatment issues

Medication can be an important part of a comprehensive treatment plan for some mental illnesses in children and adolescents. Ongoing evaluation and monitoring by a physician is essential. A monthly phone consultation paired with clinic visits every two to three months is adequate if the child's behavior is improving or becoming more stable. If not, more frequent visits and/or a change in medication may be required.

Parents need complete information when psychoactive medication is recommended as part of their child's treatment plan. Children and adolescents can also be included in these discussions. By asking questions such as those listed in "Questions to Ask" on page 53, children, adolescents and their parents can gain a better understanding of psychoactive medications.

Since all medications may produce

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Questions to Ask

Medication can be an important part of treatment for some mental illnesses in children and adolescents. However, parents need complete information when psychoactive medication is recommended for their child. By asking the following questions, children, adolescents and parents will gain a better understanding of psychoactive medications:

1. What is the name of the medication? Is it known by other names?
2. What is known about the drug's effectiveness in children with similar symptoms?
3. How will the medication help? How long before we see improvement?
4. What side effects commonly occur with use of this medication?
5. What side effects occur more rarely? What serious side effects are possible?
6. Is this medication addictive? Can it be abused?
7. What is the recommended dosage? How often will the medication be taken? What times of day should the medicine be taken?
8. Are there any laboratory tests, such as heart function or blood tests, that need to be done before taking the medication? Will any tests need to be done while using the medication?
9. Will a psychiatrist be monitoring the child's response to the medication, making dosage changes if necessary? How often will the child's progress be assessed? And by whom?
10. Are there any other medications or foods that should be avoided while taking the medication?
11. Are there any activities that should be avoided while taking the medication? Are precautions recommended for any other activities?
12. How long will the medication be needed? What factors will lead to a decision to stop this medication?
13. What do we do if a problem develops—for example, if the child becomes ill, if doses are missed or if we see signs of side effects?
14. What is the cost of the medication (generic vs. brand name)? Is it covered by health insurance? What sort of financial assistance is available?
15. Do members of the school staff need to be informed about this medication?

If, after asking these questions, parents still have other questions or doubts about treatment with medication, they can ask for a referral to another child/adolescent psychiatrist for a second opinion. Parents seeking referrals to a local child/adolescent psychiatrist may contact the American Academy of Child and Adolescent Psychiatry (AACAP), 3615 Wisconsin Ave. NW, Washington, DC 20016; (202) 966-7300.

This sidebar was adapted from "Questions to Ask about Psychoactive Medications for Children and Adolesecents," part of the FACTS FOR FAMILIES series of fact sheets from AACAP. The series includes 53 fact sheets on a variety of topics related to the mental health needs of children and adolescents. To obtain a complete list of topics, send your request, with a self-addressed, stamped envelope, to AACAP Public Information, 3615 Wisconsin Ave. NW, Washington, DC 20016. Free copies of up to five individual fact sheets can be obtained by mailing a self-addressed, stamped envelope to the same address.

A complete set of all 53 fact sheets may be purchased for $18 (includes postage). Make checks payable to "AACAP," and send to AACAP Public Information, P.O. Box 96106, Washington D.C. 20090-6106.

harmful side effects of varying degrees, parents always need to ask about potential side effects. Although certain side effects may be characteristic for a specific medication, any drug can occasionally produce unique, unusual changes. Parents may want to contact the prescribing physician whenever they observe *any* major changes in their child's behavior—expected or unexpected—while on medication. If side effects persist, it may be time for an alternative medication.

The Ayres have had to adjust Andy's medication on a few occasions. "At one point, the Tegretol affected Andy's liver functioning, and his white blood cell count started to fall off quite drastically," said Carter. "Lithium has been the most successful."

Children with special health care needs may have some unique issues their parents can explore with the clinical team before initiating treatment with medications. For starters, the team should examine the potential physical side effects of certain medications in areas where the child may be especially vulnerable. For example, parents of children with heart conditions might wish to consult a cardiologist before proceeding with psychoactive medications. Some of these medications—the tricyclic antidepressants, for example—can affect the heart's rhythm, slowing and accelerating the heartbeat irregularly.

Sometimes, too, there can be an undesired interaction between certain psychoactive medications and other medications being used for conditions related to a developmental disability. One medication might dampen the effectiveness or exacerbate the side effects of the other. Parents with children on anti-seizure medication, for instance, need to remember that certain other medications can reduce the effectiveness of the anticonvulsant, while others can exaggerate its potency to toxic (poisonous) levels.

Parents need to describe the details of their child's current medication program to their child's psychiatrist. It's also important for the other medical professionals involved to confer with the psychiatrist, with each other, and with the parents, so each has a thorough understanding of the treatment plan that can be taken into consideration when any new medication is prescribed.

Not a "cure"

Psychoactive medications, when used as part of a comprehensive treatment program, can offer a degree of control over mental illnesses, but "cures" are still unavailable. Andy, now 14, continues to struggle, but his parents are grateful for the progress he has made.

"Andy still has some impulsive behaviors, but I think he's feeling a lot better about himself," says his dad. **EP**

—Jason Roeder

Jason Roeder was an editorial intern with EXCEPTIONAL PARENT. He is now completing an internship at BOSTON magazine.

The following experts generously assisted with this article:

- *James Leckman, M.D., Neison-Harris Professor of Child Psychiatry and Pediatrics, Child Study Center, Yale University School of Medicine, New Haven, CT.*
- *Edwin Mikkelsen, M.D., Associate Professor of Psychiatry, Harvard Medical School; Medical Director, Mentor Clinical Care, Boston, MA.*
- *Luke Tsai, M.D., Professor of Child Psychiatry and Pediatrics and Director of Developmental Disorders Clinic, University of Michigan, Ann Arbor, MI.*

Some of the information in this article was adapted from:

- *The FACTS FOR FAMILIES series of fact sheets from the American Academy of Child and Adolescent Psychiatry. For more information on this series, see "Questions to Ask" above.*
- *LET'S TALK FACTS ABOUT: CHILDHOOD DISORDERS, a 15-page booklet produced by the American Psychiatric Association (APA). For a single free copy, write to APA, Division of Public Affairs, Dept. EPM, 1400 K St. NW, Washington, DC 20005. For information on bulk orders, call (800) 368-5777.*

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MOVE International

GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

MOVE International is about people who care. About dedicated individuals who took a hard look at their past work and had the courage to call it a failure. About people who are challenged by immobility, and about the people who care about them. People like Linda Bidabe.

ADMITTING FAILURE

MOVE—Mobility Opportunities Via Education—began with children who had severe mental and physical disabilities and attended the Blair Learning Center in Bakersfield, California. In the early 1980s, the staff of the center decided to take a cold, hard look at the outcomes of their efforts with these children.

The results of this evaluation were depressing: Sixty-three percent of the students who had profound disabilities and were nonambulatory were functioning *below* the six-month level of motor skill development. These children had entered the educational system at three years of age. However, by the time they left school at age 22, many seemed to have *fewer* skills than when they had entered. Babies were growing into young adults with painful deformities and bleak futures. Many students had such poor head and trunk control that they could not sit unsupported; most could not feed themselves or use the toilet.

Linda Bidabe, an educator working for the Kern County Superintendent of Schools Office (which operates the Blair Center) realized that one reason for this apparent regression in skills was that the children spent most of their time reclining in bean bag chairs or strapped into wheelchairs. As they grew older and heavier, gravity became the enemy. With increasing size and weight, the children became less able to bear weight on their legs, pull up to a sitting position or take reciprocal steps. With lack of use, their limbs became less flexible and less amenable to manipulation or therapy. Over time, the children's educational program turned into custodial care; teachers and therapists had to spend so much time caring for the children's basic needs—positioning, feeding and toileting—that there was little time left to help the children learn new skills.

PILOT PROGRAM

A dynamic and gifted teacher, Linda refused to accept this situation as the inevitable result of severe disabilities. In the summer of 1986, Linda's office created a mobility pilot program to focus on just three skills—sitting, standing and walking. The students involved in the program were between the ages of six and 16; all had multiple disabilities. None of the children had ever walked. Only one had any speech. The program involved integrating every aspect of the educational curriculum into a physical activity that could help teach specific motor skills. For example, during speech therapy, the children were placed in an upright stander instead of a wheelchair. During art, students would sit in chairs that had been slightly modified to provide support and prevent falls but that would encourage their back and stomach muscles to work throughout the duration of the activity.

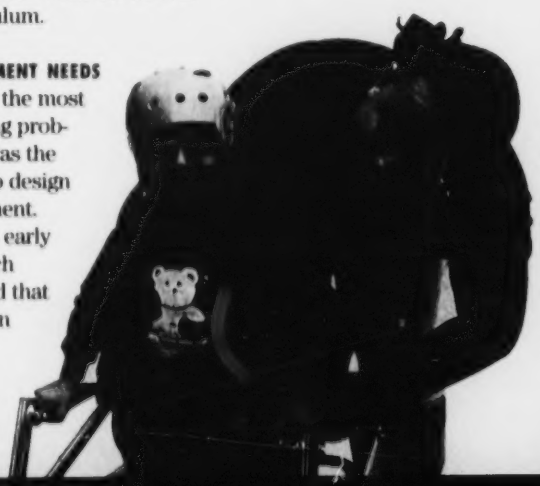
The results of the pilot program were astounding. The teachers worked with individual children throughout the day on specific motor skills, such as sitting or standing. Within a matter of days, an individual child would progress from tolerating this activity for a few seconds, to sitting and standing for an hour or more.

Not only were the children mastering the motor skills that had been the original objectives of the program, they were also becoming more alert and interactive—laughing and making attempts to communicate with their teachers and with each other. Giving a child a means of independent mobility—and the opportunity to make choices—became the foundation for the development of additional skills.

Teachers were amazed. Parents were thrilled. It was obvious the program needed to be defined and expanded. Through a Rotary International fellowship, Linda spent a year in Australia replicating the early successes of the program and doing research to write the MOVE curriculum.

EQUIPMENT NEEDS

One of the most pressing problems was the need to design equipment. Linda's early research showed that children



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AMBER STEENBOCK

Living a life on the move

Ever since I can remember, I have wanted to get around and go places. This might have something to do with moving being a big part of my childhood.

I was born in Japan. About three months later, my parents and I moved to Colorado. There, my two younger sisters made their appearances.

Even as a very young child, I seldom allowed my physical disability (quadriplegic spastic cerebral palsy) to interfere with my perpetual goal of being on the move. After mastering the art of rolling, I found this to be a relatively fast and efficient mode of travel for my little body.

After kindergarten, we moved to Kentucky. There, I got my first motorized wheelchair. The wheelchair didn't go very fast, but I enjoyed my new freedom, and thought I was hot stuff. So did my new neighborhood friends. Together, we discovered a great new way to have fun. A jump rope was tied to my chair handle, and six or eight roller skaters were given a "high-speed" tow.

A couple of times, I even ran away from home. I packed my little toy suitcase with my favorite things and drove angrily down the sidewalk—but I always changed my mind by the time I turned the first corner.

After eighth grade, we moved to our farm in Oregon and put down some roots. My sisters and I attend Marshfield High School, where I am a senior.

Amber Steenbock enjoys the view from her family's deck with buddies Scooter (on lap) and Rebel.

When my physical therapist introduced me to the MOVE program at the beginning of the last school year, I was interested. She told me that this was no ordinary program. Rather than the therapists telling me what to do, I would be in control of the pace and order in which I progressed. That sounded very cool. So, we went to work.

I wasn't very impressed in the beginning. Learning to balance in a regular chair was hard work. It took a long time and it wasn't much fun. But after I mastered that skill, things started moving faster. Next, I worked on "prompted" standing for three minutes, and then prompted walking, supported from the front or the rear.

In December, I met a brilliant, fun and incredibly understanding woman named Linda Bidabe, the creator of MOVE. Linda brought me a Rifton Gait Trainer. I stood there for a minute, feeling an awesome sense of control. This was going to be the first time I would walk under my own power. I took off across that cafeteria, and I've never looked back.

The Gait Trainer is a walker with adjustable, removable prompts. Already, my "training wheels" have been removed; next I'll lose the seat.

MOVE has opened doors for me. Transfers are easier. I eat lunch in a regular chair. I walk the halls after school and chat with friends. I am able to "dance." Almost every day, I gain confidence, and am surprised by new or better abilities.

–Amber M. Steenbock

Amber M. Steenbock, 17, lives with her sisters Erin, 16, and Audrey, 14, and parents, Mark and Deborah, on a family farm in Coos Bay, Oregon. Amber loves reading, writing and using her computer. She also enjoys working with small children; one of her goals is to become an elementary or pre-school teacher.

with profound disabilities often required more than 2,000 practice sessions to master a single new motor skill. Public education simply did not have the resources to hire the additional personnel needed to hold children in place while they practiced these skills. The equipment that was needed to support the MOVE curriculum did not exist.

In the beginning, Linda and the staff of the Blair Center created their own equipment—using little more than old bicycle parts and imagination. Then, in 1990, Linda asked the Hutterian Brethren, members of a Christian community who operate Rifton Equipment, if they would like to work with the Kern County Superintendent of Schools to meet the unique needs of this program. The equipment had to be versatile enough to serve a variety of students with varying levels of proficiency, yet sturdy enough to be passed down from class to class as children progressed through the program. The equipment needed to support children with the most severe disabilities, yet that support had to be progressively removable as students gained strength and skills.

As a result of this collaboration, Rifton designed and created several key pieces of equipment—the Mobile Prone Stander, the Universal Chair Frame and the Gait Trainer. Each piece of equipment uses a series of "prompts"—belts or straps—that provide support to different parts of the body and can be gradually removed as a child develops skill and confidence.

THE CURRICULUM IN ACTION

MOVE takes a practical, common-sense approach to teaching children to sit, stand and walk.

For years, many doctors, therapists and teachers have believed that in order to walk, children must first learn to push up and crawl. The natural inclination of adults is to begin teaching where children start failing. Unfortunately, this approach did not work well for children with the most severe disabilities. As children worked on skills like crawling or rolling, they grew into adults who were still working on the same skills.

MOVE turned that model on its head. Instead of using a "bottom-up" model based on typical infant development, Linda began by doing a task analysis of the skills the children would need to lead functional, dignified lives—skills like bathing independently, feeding themselves and using the bathroom.

MARKUS SMITH

Working toward a dream

Markus' physical therapist, Darron Veh, called me in October of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral palsy. We had "tried" many different things to improve his motor abilities, but Markus had made little progress in the last several years. Markus could stand in a prone stander, but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron introduced us to MOVE and the Gait Trainer and Mobile Stander. Markus loved the stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Gait Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his every little success. His self confidence began to grow.

A year ago, Markus told a doctor, "My greatest hope is to walk someday." He was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Gait Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said, "I love having a desk like the other kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

–Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh, P.T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.

Instead of starting at the point where a child begins to fail, the MOVE curriculum starts at the point where he or she begins to succeed. MOVE starts with real life skills.

Upon entering MOVE, a child is assessed starting at the *highest* skill level and moving *down* to the first level at which he or she demonstrates proficiency. If, with support, a child can bear weight and move his or her legs reciprocally, why work on the skill of crawling? With continued practice and the application of MOVE principles, many can learn independent movement.

MOVE GOES INTERNATIONAL

The success of MOVE has been phenomenal. The curriculum has been translated into seven languages, and training workshops are conducted throughout the United States and Europe. Today, MOVE International, a not-for-profit organization, is supplying information about the MOVE program to people in all parts of the world.

For more information, contact:
MOVE International, City Center; 1300 17th St., Bakersfield, CA 93301; (800) 636-4560 (voice).

SIMON THORPE

Hard work leads to greater independence

Simon Thorpe received a 1993 McDonald's Child of Achievement Award from British breaststroke champion Nick Gillingham and British television star Trudi Goodwin.

In 1993, 11-year-old Simon Thorpe received a McDonald's Child Of Achievement Award for sitting on a standard chair at a table and feeding himself. For Simon, these "simple" tasks represented a major achievement.

Simon was born with profound learning and physical disabilities—including difficulties in moving and controlling all four limbs. His family was determined that Simon should live as full and active a life as possible. Together, the family worked to encourage Simon to move.

In 1984, Simon began to receive home-based physical therapy. At five, he began to attend Gorse Bank School in Chadderon, England, a special school for children with learning difficulties, where therapists, teachers and parents work closely together.

By 1992, Simon was able to sit in fully supported seating and could tolerate being placed upright in a standing frame. However, he was unable to feed himself, sit on a standard classroom chair or walk.

In June 1992, with the backing of school officials, the physical therapy department introduced MOVE. Simon's participation required teamwork from parents, teachers and therapists; but above all, it required hard work from Simon.

After one year, Simon was able to sit on a standard chair without support and feed himself. Following major surgery to his legs, Simon is now learning to walk.

–P. Norbury

Mrs. P. Norbury, M.C.S.P., S.R.P., is supervising physiotherapist of the Learning Difficulty Services department at Gorse Bank School in Chadderton, England.

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Circle # 41

James Meadours

"Self-advocacy makes me feel good about myself."

James Richard Meadours, 28, is a paid VISTA volunteer working for the Tulsa Arc in Tulsa, Oklahoma. In this position, Meadours, who has mental retardation, works with People First, a self-advocacy organization. He helps to set up new self-advocacy groups and to support existing groups for people with developmental disabilities.

In September 1995, James was a featured speaker at the National Collabor-ative Academy on Mental Retardation sponsored by the President's Committee on Mental Retardation. This article is adapted from the speech he prepared for that event.

Eighteen-month-old James spends an affectionate moment with his mother, Ruth Ann Meadours, and infant brother, Joe.

People with mental retardation and developmental disabilities have come a long way. I remember five years ago when I joined the board at the Tulsa Arc. It was my first time to serve on a board of any kind. Inside of me, I wondered if I was going to do well or if I would fail.

At first, I did not understand my role as a board member, but I grew as the organization grew. When I started serving on the board, the center had only three staff members. Now we have 15 staff members working across the state, and I am one of them. Back then, I did not imagine myself doing this job today.

Duck, duck, goose

I remember when I was a child. It was hard to make friends. Kids made fun of me and teased me.

School was a challenge, too. When I was in fifth grade, they put me in a gym class with second-graders. That made me feel left out. In the second-grade gym class they played that little kids' game called "duck, duck, goose." The fifth grade gym class played flag football. I went home and told my mother. The next day she called the school to complain. Afterwards the teacher was angry with me because he thought the second-grade class was right for me.

It wasn't until high school that I was able to challenge myself. I took regular classes. It was hard but at least I tried. In the eleventh grade I got on the honor roll at high school. I really appreciated my teachers' support. I wish everyone could be in regular classes.

Transitions

The hardest part of leaving high school or an institution is having the ability to make something good for yourself. We need help to find jobs in the community instead of in sheltered workshops. We need better transition support. I see a lot of people get stuck in corners and never have a chance to work at a real job. It's better if you let us make mistakes in the so-called "real world."

It is important for us to have good support and real friends. We don't want paid staff to take of care of us all the time. I was in a workshop for about three years before leaving high school; I worked during the summer months. At the time, I thought the workshop job was okay.

After high school, I moved to a group home. At the time, I thought it would be great to get out of my stepmother's hair, and my dad's hair, too. But it was hard for me. I was the only person in my group home who had never lived in a institution. I felt my family fading away from me. I felt alone.

Making friends

I was the only Catholic at our group home. One day I saw an announcement in the church bulletin. It talked about a dance for people who are 18 years old to "40-something."

I wanted to go, but I was scared. First of all, I did not know what they meant by "40-something." Also, I did not know what they would say about me living in a group home or if they would want a person with mental retardation coming to the party.

But I went anyway, and I really enjoyed myself. I made friends at the party—like my best friend, Matthew, and his girlfriend, Mary. Now Matthew and Mary are married and have a little boy named Tommy.

Some of my new friends were on the church's softball team. They invited me to watch them play softball on Saturday after the party, but I couldn't go because I had to go to the workshop. The next week, I saw my new friends after church and they gave me a ride to the game. A year later, I started playing softball with them. Now I have been playing softball for seven years.

Living independently

Meanwhile, there were a lot of changes at the group home. They got a new executive director, and there were a lot of new rules. For example, residents had to take a test to earn a key to the home.

In 1990, I had a meeting with staff members and my

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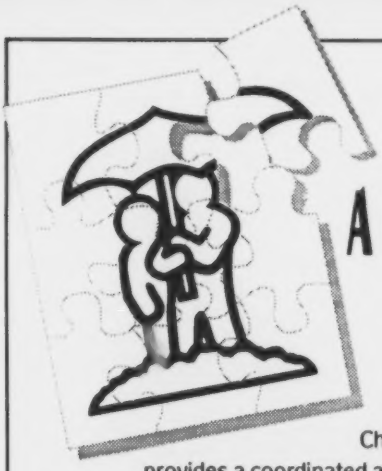

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Circle #275

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stepmother and father to discuss my goals. I said that one of my goals was to move out of the group home. The staff told my parents I should wait until I was 30 years old.

Later, I was talking to my friends, Matthew and Mary and some others, while we watched the Super Bowl. I told them I wanted to move out of the group home.

I thought they would tell me I should stay at the group home. Instead they asked if I was free on Saturday.

I told them, "Yes, I am."

That Saturday, they helped me look for an apartment. We looked at a lot of apartments, and the last place we saw seemed like a good match for me.

The staff people at the group home called my stepmother and father. My parents questioned me about my plans. I stood tall and told them I was ready to live independently. Three weeks later, my friends helped me move into my new place.

I decided to play a joke on my friends. I called and left a message on their answering machine saying I burnt down the kitchen after my first night's stay in my own apartment.

I still enjoy living independently. I get support from People First, Best Buddies (a group that pairs people with and without disabilities) and other programs.

James (right) enjoys Christmas dinner with Aunt Sandy (left) and Cousin Lara (center).

James saved a special Christmas hug for his favorite uncle, Paul Bankies.

Becoming a self-advocate

Everyone should try to be an advocate for someone. Even be an advocate for yourself! Sometimes self-advocacy is hard. Some people do not take us serious when we say things to try to make our lives better.

I started attending the People First group in Tulsa in 1988. My only reason for going

continued on page 62

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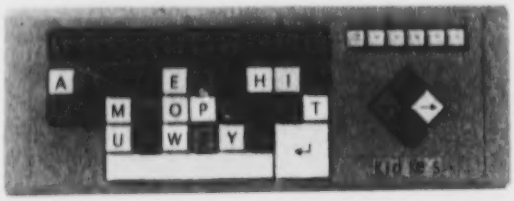

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Circle #88

continued from page 61

to that first meeting was to find out how to change the address on my voting card after moving to the group home. I just wonder sometimes—what if I didn't happen to change my voting card? I probably would not be involved in People First or belong to other groups helping my peers. I probably would still live in a group home and work at a workshop. I probably would have done nothing to better myself.

I have really enjoyed serving as a self-advocate with many different groups. I share my experiences as a person with mental retardation. Other people can learn from my experiences. I have learned a lot, too. It makes me feel good about myself.

In April 1994, James traveled to Washington, DC to attend The National Reform Agenda and People with Mental Retardation: Putting People First, a meeting sponsored by the President's Committee on Mental Retardation. Before his participation on a panel of self-advocates, James chatted with Donna Shalala, Secretary of the U.S. Department of Health and Human Services, and Chair of the President's Committee.

"Listen to us!"

Last April, when the President's Committee on Mental Retardation asked me to come to Washington, DC, I felt that I would not only represent myself, but all my peers from Oklahoma. One close friend told me that professionals in the field of mental retardation would start asking me to speak all over the country. That made me a little nervous. My friend told me, "You feel like you need to know all the answers, but you don't. You just need to be yourself and tell how you really feel about things."

This is how I really feel: My dream is to see equal rights for people with mental retardation. I know many parents and professionals share this vision. People with mental retardation can help make this vision a reality. Listen to us. If you say something that might be over our heads, ask questions to make sure we understand. If we don't understand at first, use words we can understand so we can share information. Help us participate and give us support when we need it.

One of my favorite quotes is by Goethe. The quote is about the power of expectations, and it goes like this: "If you treat an individual as he is, he will stay as he is. But if you treat him as if he were what he ought to be and could be, he will become what he ought to be and could be." **EP**

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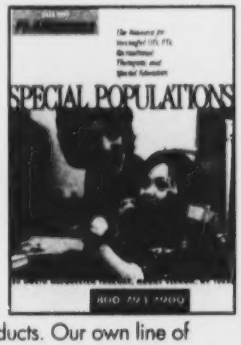

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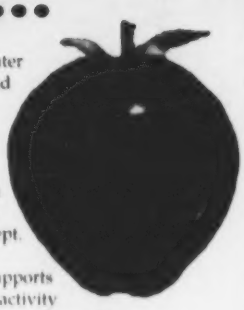

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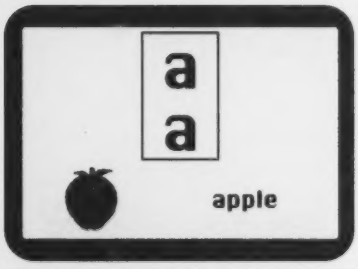

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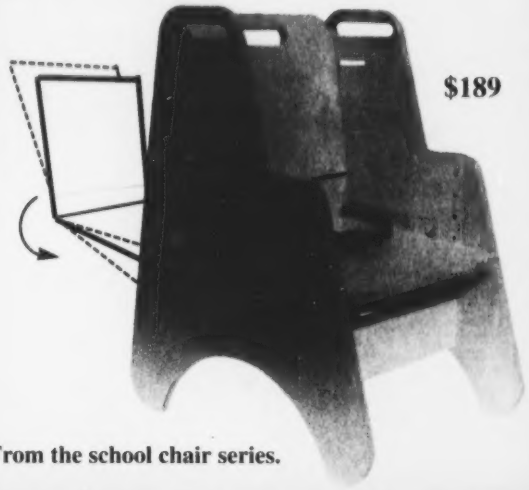

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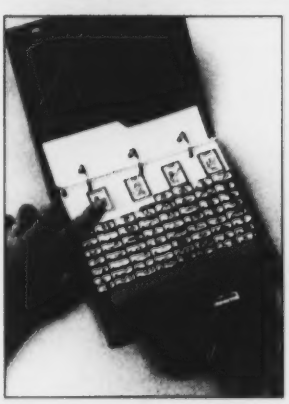

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by David Hirsch, M.D.

Feeding Aversion

Q My daughter is now two and a half years old. She was born at 28 weeks gestation and spent almost two months in the hospital requiring ventilation, oxygen and total peripheral nutrition (TPN), meaning all required nutrients were given intravenously. Before she was able to nipple feed, she was given formula through nasogastric feedings (in which a plastic tube was passed through her nose and esophagus, and into her stomach). She has one of the more common neurological complications of prematurity, spastic diplegia, a form of cerebral palsy resulting in spasticity or severe increased tone typically involving the lower extremities. She uses AFOs (ankle-foot orthotics or braces) and receives physical and speech therapy. Her developmental skills are only slightly delayed.

My concern is with what her speech therapist and pediatrician agree is a feeding aversion. It seems to be getting worse. She has not gained much weight in the last six months. She will take small amounts of milk from a bottle, but little else without a battle. Feedings take more than an hour, and I have to fight to get every spoonful into her. At the end of the meal, we are both frustrated. Now her pediatrician and I are considering a gastrostomy feeding tube to allow her to get adequate calories and fluids without the heartache. Do you have any thoughts about this problem? Is it very common?

A This is a difficult situation for the whole family. I have seen a number of children with similar problems who have been very sick either as newborns (usually with complications of prematurity) or have been very ill in the first year of life. I assume that your daughter's physicians have ruled out any physiological problem such as reflux (the abnormal backflow of stomach contents up the esophagus), recurrent aspiration (in which solids or fluids, usually stomach contents or food in the process of being swallowed, end up in the respiratory tract—usually the lungs—instead of in the digestive system), chronic abdominal pain, constipation or any type of swallowing disorder or other disorder of the central nervous system (brain and spinal cord) that may be responsible for her apparent feeding aversion.

If a physiological problem has been ruled out, your daughter may have a form of "conditioned taste avoidance learning." This phenomena, which sounds more complicated than it is, has been extensively described in animals, but also in older children and adults. In the case of infants and young children who were sick as newborns, it is thought to be a type of "phobia," a persistent abnormal dread or fear, often resulting in an aversion, brought on by one or more bad experiences. An example of a "bad experience" in this context would be significant vomiting or abdominal pain that may have occurred with oral feedings in the newborn period. The tastes or smells that occurred with the "bad" experience(s) remain a "stimulus," and a feeding aversion is the "response."

Unfortunately, since there often is not much variety in a young child's diet, just about any similar food or feeding experience later on can be the stimulus that brings on a feeding aversion.

Try offering a greater variety of foods that can supply the nutrition your daughter needs (you may want to consult a dietitian/nutritionist). Limit mealtimes to about 30–40 minutes, but not less than 20 minutes. If she likes milk, try a caloric supplement such as Instant Breakfast or a specialty formula, such as Pediasure, but use a cup she can handle. Her bottle may be comforting to her, but at her age and developmental level she should be using a cup.

Enlist other people to give her occasional meals. This will give you a break and the chance to see different feeding techniques (or styles) that may work well with your daughter. Try to avoid distractions during mealtime.

Stick with it. Try not to become frustrated, because your daughter will sense your frustration and become more anxious herself. You may have to consult a pediatrician who has experience in behavioral disorders (or even a psychologist) to give you more help and direction, but given enough pleasant meals and exposure to a wider variety of foods, your daughter's food aversion should resolve itself in time.

On occasion, if a child's health would be jeopardized by inadequate caloric and fluid intake, I have found it necessary to utilize nasogastric or gastrostomy feedings as a supplement, often by using a pump overnight. If this is done, however, I always recommend turning the feeding pump off early enough that child will feel "hungry" for breakfast. Check with your daughter's pediatrician about trying some of these ideas first, certainly before placing a gastrostomy tube. If the feeding aversion does not resolve itself in time—and the length of time you give it should depend on your daughter's clinical condition—then gastrostomy or nasogastric feedings should be utilized. Even so, you should continue oral feedings and try to resolve the feeding aversion so she can take her feedings orally with enjoyment. **EP**

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-5743 (Fax).

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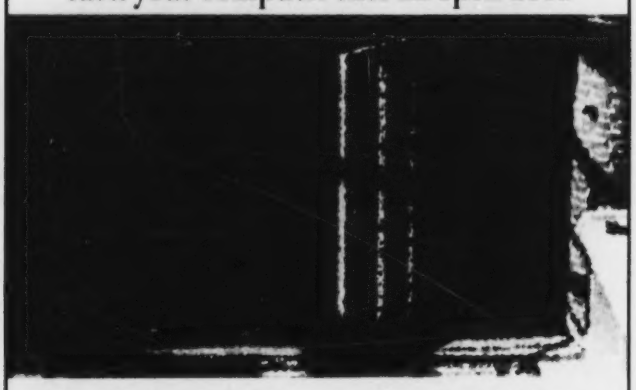

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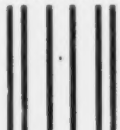

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HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Coverage for Special Formulas

Q Our four-year-old daughter has Opitz syndrome, Turner syndrome and a multitude of medical problems. She has never eaten food; she has always been on a special formula.

Since the age of 10 months, she has been fed by gastrostomy-tube. Our private insurer covered the pump and home care supplies, but not the formula. The company told us they never pay for "nutritional or dietary supplements." We contended that this formula is in no way a "supplement"—in fact, it is the only nutrient that keeps our daughter alive—but the insurer would not pay for the formula.

We're still with the same insurance company, but we've changed policies. Once more, I tried to get the formula covered, only to be told again that they never pay for it. I asked the company why they pay for home IVs but not formulas, since both help keep people alive. Their response was to ask if my daughter could be placed on an IV!

After the first few years of paying for our daughter's formula, we were very much in debt. Then we applied for Medicaid for her. Once she qualified, Medicaid covered her formula and has done so ever since.

We pay for our private insurance policy through my husband's employment. We do not want Medicaid to pay for our daughter's extremely expensive formula. We believe our private insurer, our *primary* insurer, should pay for this formula.

I believe that Medicaid monies should go to people without any other insurance. I am appalled that approximately $21,000 of taxpayers money is spent on my daughter's formula every year. Representatives of our private insurance company do not understand this reasoning; they seem to think we should not be bothering them since Medicaid is covering the formula.

This battle will be tough, but we feel we are doing the right thing. I've written to our senator, and I've filed a complaint with our state insurance commission. What other steps can I take to change the rules and regulations?

A This battle *will* be tough, but it will also be worthwhile. Many people with children who require special formulas on a daily basis may not be able to qualify for Medicaid. As you know, the economic burden of paying for formula can be difficult to bear. In addition, the government plans to reduce spending for the Medicaid program.

Although you've filed a complaint with the state insurance commission, they are unlikely to deal with this issue. State insurance commissions have the power to require an insurer to follow existing regulations, but they do not generally issue new rules.

The state legislature, however, has the authority to pass laws requiring insurers to pay for specific treatments. Over the last few years, a number of states have considered, and in some cases enacted, new laws requiring private insurers to pay for everything from routine medical tests, to diabetes-related supplies and equipment, to bone-marrow treatments.

Some states have even passed laws requiring private insurers to cover certain formulas for children with metabolic disorders. Your state legislature may consider holding hearings on the possibility of enacting new legislation that would require private insurers to cover all formulas for which Medicaid has agreed to provide coverage.

The best way to work toward that goal is through a parents' group. Precedents exist; parents have been instrumental in drafting and passing laws that address these issues. For example, in January 1994, the Massachusetts legislature passed a law requiring private insurance companies to cover formulas necessary for the treatment of phenylketonuria (PKU) and similar metabolic disorders. Prior to the passage of this law, Massachusetts parents of children with PKU had contended with the same insurance problems you face—insurers who denied claims on the basis that formulas are food, not medicine. When these parents became frustrated enough to take on the state government, they obtained the help of PKU professionals and a legislative aide to draft a bill for a law requiring private insurers to cover both formulas and special low-protein foods. The bill also prohibited companies from setting an age limit for coverage, and it incorporated all amino acid and organic acid disorders, not just PKU. Key strategies for getting the bill passed included testifying before the joint House-Senate Committee on Insurance, sending out information packets to senators and representatives and seeking letters of endorsement from various groups.

You may want to contact parents' groups in your area to see if they're interested in working on this issue. If not, you might consider organizing your own group. Let me know what happens. **EP**

EDITOR'S NOTE: We obtained information about PKU-related laws from NATIONAL PKU NEWS, a newsletter published three times a year. To subscribe, send $14 to NATIONAL PKU NEWS, 6869 Woodlawn Ave., NE #116, Seattle, WA 98115-5469.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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CONNECTIONS

The Newsletter of the National Center
for Youth with Disabilities

Students Learn *(and Teach)* Self-Advocacy

A group of high school students with a variety of disabilities got together with their teachers, Barb Vallejo and Sheryl Evelo, at South High School in Minneapolis, Minnesota, just about a year ago to talk about what it means to be a self-advocate. Does it mean going to the state legislature and lobbying for change? Maybe. But for these young people, self-advocacy is closer to home.

"You have to let the teacher know that you want to learn, that you want to do the work so that the teacher doesn't think you don't want to do the work," Demont Harris says. If you don't speak up for yourself, "You're just going to be a lost soul in the classroom."

For Krista Smith, now a student at a local community college, self-advocacy includes asking for help with problems. "There are a lot of college students out there who are 40 or 30 or 20 years old who don't even speak up for themselves, don't even ask questions. I've learned that it is really easy to do and it is really important to do because, if you don't ask questions or stand up for yourself, you're not going to get anywhere."

Youth Define Self-Advocacy

As these young people discussed the need to take control of their futures, the need to stick up for themselves, they developed a definition of self-advocacy:

"Self-advocacy is speaking and acting on behalf of your own rights," the students agreed. "It is the best kind of advocacy because no one knows better than you what your needs are. It's about making decisions that affect your daily lives from choosing your friends, what to study in school, what relationships to have, and what kind of job you want."

With that definition firmly in hand, they identified how they learned their advocacy skills and when, where and with whom they must advocate. With some funding from The Minnesota Transition Systems Improvement Initiative, Interagency Office on Transition Services, and assistance from their teachers and school staff, this group of special education high school students put together a video, "Self-Advocacy: Taking Charge," as an effort to help others learn what they have learned.

They recognized that many of the decisions made at IEP (individual educational plan) meetings can have a profound effect on their lives—both their daily lives and their future lives.

One student explains that, even though they talked about self-advocacy at IEP

Self-Advocacy
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Self-Advocacy
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meetings, it took him a couple of IEP meetings to actually say something. Then he realized that the reason why they are making the decisions is because, "I'm not saying anything. That's when I started speaking up for myself." That's when George Lewis learned that he could make many of the IEP decisions for himself.

"At my IEP, it helped writing my goals and letting them know what I wanted, what I think," Chantilly Lynch says.

Getting the Words Out

These teens realize that learning to advocate also means teaching others to respect personal needs. Some teachers need to understand what it means to have a disability and what accommodates different learning styles. Students at South High are learning to teach the teachers.

Brett Gilman thinks the best thing that teachers could do would be to understand that some people have a hard time speaking up for themselves. Teachers need to be patient. Others explain that teachers need to provide alternative ways to complete assignments.

In turn, each of these students can explain their disability and tell their teachers how it affects their learning. That way the teacher understands why the accommodation is necessary

Students agree that they need to advocate for themselves when they are with their friends. When tempted to skip class or get into trouble, they admit advocating is not always easy. One student admits that sometimes it's easier to just do what they say. Other times, like when his friends skip, he just tells them he forgot about meeting them. Youth need to use a variety of advocacy strategies.

"Self advocacy is speaking and acting on behalf of your own rights. It is the best kind of advocacy because no one knows better than you what your needs are."

Even parents need advice. One student asks why his mom was always nagging him when he got in trouble. She should nag him when he is doing right.

Self-Advocacy
Turn to page 73

Editor's Note:

When I walked into Barb Vallejo's high school classroom last spring, I couldn't tell who had an IEP and who did not. I hesitated a little and wondered how will I identify those young people who most capture my interest and imagination: adolescents with chronic illness or disability. Vallejo's students made it easy.

One young man talked about his learning disability. "You know, when I started junior high, I began having real problems. I would do the math homework but couldn't find the paper. Or I couldn't remember if I completed the assignment at all. I'd confuse one class with another." This glib, attractive high school junior could articulate his frustration. When the semester ended and he would clean his locker, he'd find all the work he'd thought he'd lost. The situation only got worse and, by high school, he was way behind his peers, feeling "dumb" and hating school.

Today, he can explain his disability to his teachers. He can tell them what accommodations he needs. "You see, each day we list out each class on this paper. The teacher writes out the assignment I have to do in class or at home. And then we organize the work." At the end of the day, Vallejo or a colleague helps him sort through the books and papers and organizes again. This self-advocate will succeed because he understands his needs and can ask for help.

Each time I meet a young person with a disability who is enthusiastic about life and feeling in control, I am certain someone has taken the time to help that youth to become a self-advocate. As parents, as teachers, as doctors and providers, our goal should be helping to build the capacity of youth with disabilities to speak out for themselves.

The story, "Speak Out: Students Learn (and Teach) Self-Advocacy," shows how one group of students learned these skills and applied them to their everyday lives. We've also provided a summary of some of the presentations made at the Great Lakes Society for Adolescent Medicine. They provide some innovative suggestions and guidance to making a difference in your community and state. Finally, Liz Latts, Information Specialist and Director of the Resource Library, has identified two projects on self-advocacy that she finds particularly interesting.

PMR

985

Help turn the C+ into a B+, the B+ into an A.

"As self-advocates, we've learned to speak for ourselves when meeting with teachers, at our IEP meetings, on the job, with family and friends, and planning our future and living independently," Rosie Lindberg-Lasko, summarizes. "Our experiences are sometimes different from those of other students. We have a lot to offer and can give advice to teachers, family, and especially other students who are developing self-advocacy skills.

For more information on self-advocacy, or for information on how to get a copy of the videotape, "Self Advocacy: Taking Charge," contact:

Transition Plus Services
807 N.E. Broadway
Minneapolis, MN 55413
(612) 627-2141

or

Minnesota Transitions Systems Improvement Initiative
Interagency Office on Transition Services
657 Capitol Square Building
550 Cedar St.
St. Paul, MN 55101

Adolescents & Advocacy:

Professionals Play Important Roles

When the Great Lakes Regional Chapter of The Society for Adolescent Medicine (SAM) planned their fall meeting, they decided they should visit the issue of advocacy. "Physicians and nurses, social workers and nutritionists, teachers and other providers can improve the conditions for adolescents with disabilities—indeed for all adolescents," says Nancy Okinow, President of the Great Lakes Regional Chapter of SAM.

Physicians can play a critical role in their communities. Steve Matson, M.D., from Milwaukee, Wisconsin, comes with a mission. So few physicians and providers are interested in the care of adolescents that there really are wonderful opportunities to increase services for this group of young people in the community. He provides some strategies for those who wish to provide adolescent health services:

- Know the area in which you work;
- Determine the needs of the young people;
- Get to know the important people in your community;
- Persuade the movers and shakers that your idea is critical to the life of youth in your area;
- Work with the media (give talks, agree to be on the local radio show); and
- Make certain the people on your team are dreamers.

Anne Dopp, R.N., M.S.N., P.N.P., from Wisconsin, says there are opportunities for advocacy and changing policy at all levels.

Providers who currently work with youth must talk to health insurance companies, to the people in benefits; show them how continuity of care for youth can increase healthy outcomes and may reduce costs.

Call your local and state representatives regularly to tell them about youth needs. If you call regularly, your issues will become familiar and you will be able to influence how your representative thinks on youth issues.

Persistence Pays

Ed Ehlinger, M.D., Director of Student Health Services at the University of Minnesota, explained that he's interested in issues if they are:

- Important to the community;
- Perceived as a public health responsibility;
- Intervention is possible; and
- Outcomes are measurable.

He suggests that advocates follow the "Natural Laws of Data and Policy Development":

Policy development occurs at all levels at all times, is incremental and not linear. Data is not always sufficient for policy development and sometimes not necessary to changes in policy. ***Miracles do happen.***

The National Center for Youth with Disabilities is a program of The Society for Adolescent Medicine and the Adolescent Health Programs at the University of Minnesota. Publication of *Connections* is supported, in part, by project MCJ-275045 from the Maternal & Child Health Bureau (Title V, Social Security Act), Health Resources & Services Administration, Department of Health & Human Services.

NCYD's mission is to improve the health and social functioning of youth with disabilities through providing technical assistance and consultation, disseminating information and increasing the coordination of services between the health care system and others. Center activities are directed at enabling youth to become full participants in their communities.

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The National Resource Library brings together comprehensive sources of information related to adolescents, disability and transition to meet the needs of professionals who work with youth with disabilities as well as their parents and others invested in their success. The database contains five files:

- *Bibliography*
- *Programs*
- *Training Materials*
- *Technical Assistance*
- *Health Care Reform*

Entry points to the Library's files are through language and issues of individual fields. Information in the files is inter-disciplinary, offering the many views that may enhance practice with adolescents and young adults with disabilities.

Programs

"Project LEAD" has focused on leadership development and inclusion of youth with disabilities in the community. Teens ages 13–18, with and without disabilities, participated in a yearly retreat to learn about legal rights and responsibilities, educational rights and self-advocacy. Social and educational activities throughout the year were used to develop leadership, promote friendships and self-esteem. Youth-oriented organizations receive training and technical assistance to make their staff, programs and facilities accessible.

For information, contact:
Project LEAD
Stepping Stones
Karen Newton
(304) 296-0150
(800) 982-8799
or
Renie Boyle
(304) 599-5286

Training Materials

"No More B.S.: A Realistic Survival Guide for Disability Rights Activists." This book is written by disability rights activists. It promotes self-advocacy, the development of self-esteem and community organization as a way of fighting discrimination and securing rights for persons with disabilities. It is written in a strong "straight-shooting myth bashing tell-it-like-it-is" style. A companion booklet is available for direct service providers. Cost is $10.00.

For information, contact:
People First of Washington
P.O. Box 648
Clarkston, WA 99403
(509) 758-1123
(800) 758-1123

Inquiries about NCYD may be directed to:
National Center for Youth with Disabilities
University of Minnesota
Box 721
420 Delaware St. S.E.
Minneapolis, MN 55455
1-800-333-6293
612-626-2825
FAX (612) 626-2134
TTY (612) 624-3939
E-mail:
ncyd@gold.tc.umn.edu

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We've Got A New Home and New Address

The National Center for Youth with Disabilities has taken the digital leap! For those of you who are interested in learning more about NCYD or our sister Center, the Center for Children with Chronic Illness and Disability, you can find us on the World Wide Web. While the pages are under construction, anyone interested can dial us up using one of two http numbers:

http://www.peds. umn.edu/Centers /ncyd gets you to the National Center for Youth with Disabilities, interactive listings, basic information on the Center and a biblography on transition.

http://www.peds.umn.edu/Centers/c3id gets you to the Center for Youth with Chronic Illness and Disability, interactive e-mail listings, basic information on the Center and recent publications.

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Speaking Out

Books and Videos About Living With Seizures

Students With Seizures: A Manual for School Nurses

Designed to promote a more accepting and understanding school environment for the more than 300,000 children with seizure disorders in the United States. The first half of the manual reviews epilepsy, seizure classifications and different treatment methods. The second half focuses on the school nurse as case manager and educator: it discusses how school nurses can educate teachers and parents about epilepsy—recognition, medication effects, skills assessments.

Catalog # 148SWS
144-Page Manual
$22.46 EFA Member
$24.95 Non-Member

School Planning for Children with Seizure Disorders

Of special interest to families in which a child with epilepsy also has a learning disability or is not doing well in school.

Describes some epilepsy-related problems that may affect learning, what kinds of service may be needed and how parents can function as full-fledged members of the school planning team. Stresses inclusion in regular school activities. A Family Video Library presentation. (1992)

Catalog # 533SCD
VHS Videocassette, 14-Minutes
$13.46 EFA Member
$14.95 Non-Member

Seizure Disorders and the School Videos I & II

Videos show actual seizures in children, describes first aid and management in the classroom, and stresses the importance of early recognition. Fears and concerns of school personnel are addressed. Reviews how epilepsy may affect learning and discusses how the teacher can make the school experience a positive one.

Seizure Disorders and the School I

(For use with Elementary School personnel)

Catalog # 521SD1
VHS Videocassette, 14-Minutes
$22.46 EFA Member
$24.95 Non-Member

Seizure Disorders and the School II

(For use with Junior High and High School personnel)

Catalog # 522SD2
VHS Videocassette, 14-Minutes
$22.46 EFA Member
$24.95 Non-Member

Speaking Out: Partners in Advocacy—Understanding the Process

What is advocacy and why is it important? This guide provides basic definitions and principles, and discusses how people can become advocates in their own right. It reviews different types of advocacy, including personal and case advocacy, systems advocacy, and legislative advocacy. (1992)

Catalog #168PAU **$5.36 EFA Member**
20-Page Guide **$5.95 Non-Member**

Speaking Out: Partners in Advocacy—Tools & Resources

Provides a wealth of information and resources for individuals, families, organizations, and parent support groups interested in advocacy. Includes sample documents: letters, complaints, IEP (Individualized Education Program) and IFSP (Individualized Family Service Plan) forms and sample testimonies which families and advocates can adapt for use in their own advocacy efforts. (1992)

Catalog #171PAT **$9.86 EFA Member**
89-Page Guide **$10.95 Non-Member**

Speaking Out: Partners in Advocacy—Family Action Guide

Advocacy includes: identifying an unjust situation, developing strategies and planning action to bring about change. Discusses why families must be advocates for their children. Provides a clear eight-step process to help you get started as an advocate and identifies the skills and time commitment necessary for effective advocacy. Presents examples of case advocacy and discusses opportunities for advocacy in your community. (1992)

Catalog #169PAF **$8.96 EFA Member**
50-Page Guide **$9.95 Non-Member**

School Planning: A Guide for Parents of Children with Seizure Disorders

This guide describes some epilepsy-related problems that children and youth may face in the areas of academics, school achievement and social development. Suggests ways parents can take a proactive approach to ensure appropriate testing, placement and achievement of educational goals for their children. Sample IEP's included. (1994)

Catalog # 217GSP **$11.66 EFA Member**
125-Page Guide **$12.95 Non-Member**

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WHAT'S HAPPENING

Video Focuses on Telecommunications

Independence through Telecommunications: A Guide for Parents of Deaf and Hard of Hearing Children, an 18-minute video from Gallaudet University's Technology Assessment Program, explains how visual telecommunications technology can provide deaf and hard of hearing children with access to the telephone. The video features open captions, on-screen explanations in American Sign Language (ASL) and voice narration throughout. Focusing on technologies such as TTYs, relay services, fax machines and on-line services, the video features easy-to-understand explanations and testimonials by parents of children who use telecommunications devices and services. To order, send $5 (includes postage) to GRI Dissemination Office, Hall Memorial Building S-444, Gallaudet University, 800 Florida Ave. NE, Washington, DC 20002; (202) 651-5257 V/TTY.

Bridges To Reading is a comprehensive kit containing information, tools and references designed to be a first source for parents of children with learning disabilities associated with reading. The kit contains eight step-by-step booklets that answer questions about identification, testing and educational rights, along with reference guides on a variety of other topics. *Bridges to Reading* can be ordered from Parents' Educational Resource Center, 1660 S. Amphlett Blvd., Ste. 200, San Mateo, CA 94402-2508; (800) 471-9545. Cost is $20; complimentary copies are available to those who cannot afford this amount.

SSI/SSDI Help

Confused about Social Security benefits? Help is just a toll-free phone call away! The Benefits Resource Network, operated by Kennedy Krieger Community Resources in Baltimore, Maryland, answers questions about Social Security benefits (Supplemental Security Income and Social Security Disability Income) and Social Security Admin-istration work incentives. Call (800) 677-9675 (or 410/327-7122 in the Baltimore area) Monday through Friday, 9 a.m. to 5 p.m., EST.

Chronic Fatigue and Immune Dysfunction Syndrome

Chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS), is an illness characterized by incapacitating fatigue, neurological problems and a constellation of symptoms that can resemble other disorders including mononucleosis, multiple sclerosis, fibromyalgia, AIDS-related complex (ARC), Lyme disease, post-polio syndrome and autoimmune diseases such as lupus. The CFIDS Association of America has put together a package focusing specifically on children's issues. The package includes information on the physiological, psychological, educational and social aspects of CFIDS. Each package costs $10. Contact CFIDS Association of America, P.O. Box 220398, Charlotte, NC 28222-0398; (800) 442-3437; (704) 365-9755, fax.

CD-ROM Library of Disability Information

The *Cooperative Electronic Library on Disability*, newly-released on CD-ROM, contains data on products and services for people with disabilities, as well as information resources on disability. The CD-ROM is compatible with both IBM PC (DOS or Windows) and Macintosh computers. Contact Trace Center Reprint Service, Waisman Ctr., University of Wisconsin, 1500 Highland Ave., Rm. S-151, Madison, WI 53705; (608) 263-2309 (voice); (608) 263-5408 (TTY). Cost is $27.

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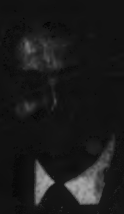
DREAMMS@

An official information dissemination point for the UCP Assistive Technology Funding & Systems Change Project

As PBS's critically-acclaimed children's series, The Puzzle Place, enters its second season in January 1996, Kyle (far right, in wheelchair) will be joining the cast in an expanded role. The series, focusing on the adventures of an ensemble of puppet "kids" of diverse backgrounds and ethnicities, introduced Kyle in the "Willing and Able" episode of its premiere season.



"EXTRAVAGANZA"
Television is important for America's disability community. The network's programming helps Americans with disabilities move into mainstream life by changing perceptions.

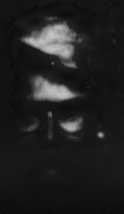
SENATOR BOB DOLE

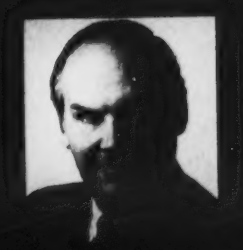
"EXTRAVAGANZA"
not only gives people with disabilities a new means of communication, but television gives all Americans an opportunity to maximize abilities.

SENATOR TOM HARKIN

As one of 49 million Americans who happens to have a disability, like I happen to have epilepsy, I'm very excited about EXTRAVAGANZA. It uses the extraordinary power of television to communicate ideas and positive role models for our complex society.

TONY COELHO, Chairman
President's Committee
on Employment of People
with Disabilities





Please join March of Dimes and EXTRAVAGANZA. With your help, we can improve the quality of life for Americans with birth defects and other disabilities. And we can offer quality programming the whole family can enjoy.

DR. JENNIFER L. HOWSE
President
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Join with us at Easter Seals and EXTRAVAGANZA. We want to share vital, accurate information. We want to brighten American homes from coast to coast with good, quality television.

JAMES E. WILLIAMS, JR.
President and CEO
National Easter Seal Society

We're delighted to join EXTRAVAGANZA in the "Calling on Cable" campaign. I hope you will become a part of the effort to bring this exciting network to every home in America.

ELAINE L. CHAO
President and CEO
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"EXTRAVAGANZA"

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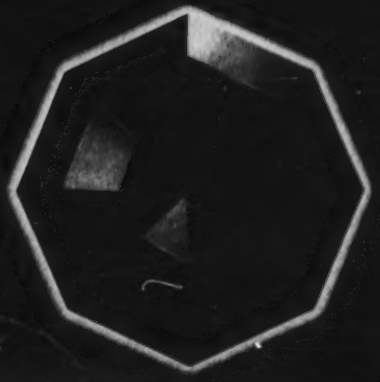

AMERICA'S DISABILITY CHANNEL

MEDIA

Written by 25 leading medical experts, MEDICAL & SURGICAL CARE FOR CHILDREN WITH DOWN SYNDROME: A GUIDE FOR PARENTS *provides in-depth, easy-to-understand information on specific conditions that are common among children and adults with Down syndrome. This book is available from Exceptional Parent Library (800/535-1910). The following is an excerpt from chapter eight, "Ear, Nose and Sinus Conditions of Children with Down Syndrome," by Kevin Kavanagh, M.D.:*

Children with Down syndrome may have a variety of ear, nose and throat (ENT) problems. Many of these problems are easily detected and may worry parents, but they typically correct themselves as children grow older. These conditions include sinus drainage, drooling, mild blockage of the nasal airways and tongue protrusion.

Other conditions may be less apparent and commonly go unnoticed by the family. Unfortunately, these problems are often more serious. They may include hearing loss and more serious blockage of the nasal airways. When any of these conditions are detected, they should be promptly treated.

Though the above list may seem long, not all children with Down syndrome will have these conditions. If your child has one of these conditions, talk with your primary health care provider such as a nurse practitioner, pediatrician or family practitioner. They can refer you to an ENT physician if necessary. For typical ear, nose, and throat conditions, treatment for children with Down syndrome is the same as for other children. However, some circumstances that call for special considerations do exist…

Sinusitis

Sinuses are the small cavities in the cranial bone located behind the nose. They serve as air passages that open off the main nasal airway. They act like a sounding board and affect the quality of speech greatly. When sinuses become filled with fluid, as they do when there is an infection, the quality of speech changes.

Because of the relatively small size of the nasal cavities in children with Down syndrome, sinusitis (sinus infection or inflammation) is common. So, too, is drainage from the nose (runny nose), because nasal drainage is often due to infection or inflammation of the sinuses. Eight out of 10 children with Down syndrome have persistent nasal drainage. Although most children have runny noses occasionally, children with Down syndrome can have this problem much more frequently and for longer periods of time. For most children with Down syndrome, the problem decreases as they reach adulthood.

If nasal drainage is thick and yellow-green in color, this suggests a possible bacterial infection. Initial treatment may be with antibiotics. If the drainage starts up again soon after you stop giving your child antibiotics, your primary health care provider may prescribe a low-dose antibiotic to be given over a long period of time (months to years) to prevent a return of the infection. The side effects are usually minimal; however, in some children, the antibiotic can alter the bacteria that live in the GI system and result in diarrhea, allergic reactions and failure to kill the targeted bacteria.

Sometimes it is suggested that modifying your child's diet can reduce sinus infections, but there has been no scientific evidence that this works. Some allergists prescribe nutritional modifications for children who have shown an allergy to some specific food and who have persistent sinus infections.

If your child's drainage is clear, your child may have allergies. In this case, your doctor may prescribe antihistamines or decongestants. In a formal survey, six of 10 patients with Down syndrome obtained relief from drainage and other allergy symptoms when they used antihistamines or decongestants. However, those medicines make some children sleepy. In other children, they may cause increased activity. These symptoms usually go away in about two weeks. There are no studies showing that children with Down syndrome are more prone to allergies than other children.

If your doctor suspects that your child has a serious sinus infection or inflammation, he or she will usually ask for x-rays of the sinuses. In some cases the doctor may order a CT scan of the sinuses. A CT (computerized tomography) scan is a special x-ray test that gives a clearer view of the sinuses and can be helpful in making a decision about whether or not surgery is needed.

As a last resort, surgery to promote sinus drainage is an option. This should only be performed if the drainage is excessive or your child has recurrent sinusitis with fever. The most common sinus surgery involves placing a drainage hole or "window" in the sinus located in the upper jaw (maxilla). This surgery is done under general anesthesia. More extensive sinus surgery is only done as a last resort in children under the age of eight… In these young children, the sinus cavities are small, the operation is technically more difficult, and results are often unpredictable. **EP**

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Coming in December...

An excerpt from* CEREBRAL PALSY: A COMPLETE GUIDE FOR CAREGIVING. *This book, written by a team of experts associated with the Cerebral Palsy Program at the Alfred I. duPont Institute in Wilmington, Delaware, addresses the many complexities and uncertainties related to a diagnosis of cerebral palsy. At the same time, it provides the information parents, grandparents, caregivers and health professionals need—everything from medical, educational and psychosocial implications of this diagnosis, to wheelchair maintenance and dental care.

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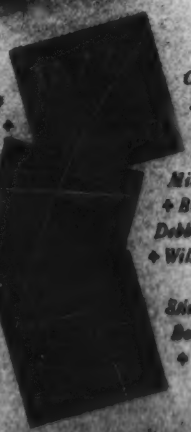

BLUE NOTE

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The Special Olympics Christmas Albums.

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EXCEPTIONAL PARENT *Library*

You can order any of the books listed here with the coupon below or by calling (800) 535-1910

DOWN SYNDROME

MEDICAL & SURGICAL CARE FOR CHILDREN WITH DOWN SYNDROME
A Guide for Parents
L. KUMIN, PH.D.,CCC-SLP
Designed to give parents a complete and easy-to-understand overview of specific medical conditions that are more common among children with Down Syndrome.
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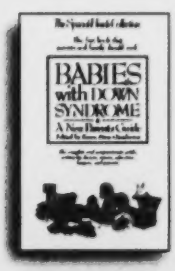

BABIES WITH DOWN SYNDROME
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ED. BY KAREN STRAY-GUNDERSEN
The complete guide for new parents of babies with Down Syndrome. Written by professionals and parents, this book covers everything new parents need to know.
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DOWN SYNDROME
Birth to Adulthood, Giving Families an Edge
J.E. RYNDERS, J.M. HORROBIN
This new book is an invaluable guide for parents of children with Down syndrome, as well as the professionals who help advance whole-family development.
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GENERAL

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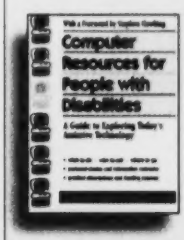

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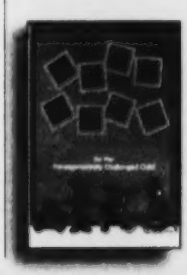

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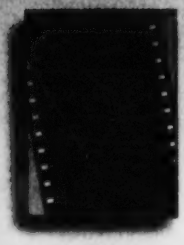

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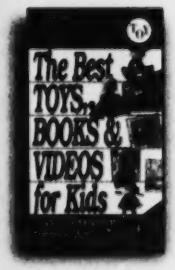

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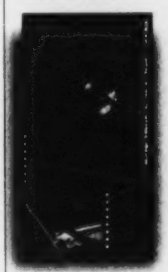

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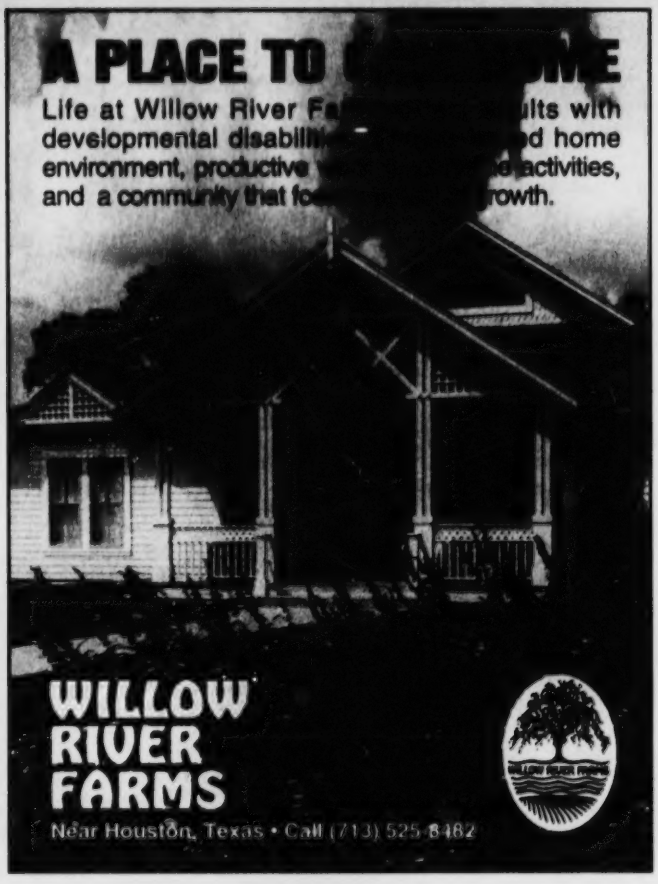

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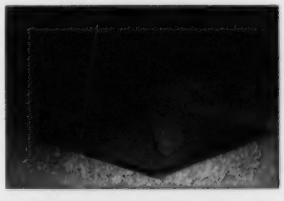

BabySmart, Watchung, NJ, 07060

Circle # 197

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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(617) 894-0069
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U.S. Medical Corporation
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Consumer Care Products, Inc.
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Our Differences Make Us Special

by Aaron Wolfson

Avi is all smiles at the end of his ride down a slide at the school playground.

A pair of wizards! Aaron and his brother Avi worked magic together during a Halloween celebration two years ago.

Imagine a world where everything is the same. It would be pretty boring, right? That's why people who are different should be treated with respect.

People with disabilities are among those people who are different. Some don't talk, walk, read or write as we do. Many of us think that people with disabilities aren't as smart as we are.

Henry David Thoreau said, "If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music he hears, however measured or far away."

This is what Thoreau's words mean to me: if you learn at a certain pace, and your brother learns at a different pace, then let him learn at that pace. Don't force him to learn at your pace. Who says that his level of learning is any worse than yours? He is distinctly himself.

These thoughts refer to my experiences with my younger brother, Avi. He has special needs. He gives me a happy feeling, makes me laugh like a hyena and gives my day a great start with his bright and beaming smile!

The school district has given Avi a technical label—"mildly mentally handicapped"—which means he can receive certain educational services. This label creates a picture in my mind of Avi riding down a conveyor belt. A machine slaps a label on his head. The label reads, "This is an Avi and he is handicapped."

But the label does not tell you who Avi really is—that he plays football, collects dinosaurs and gobbles down hot dogs. I know these things about Avi because I've spent lots of time with him and I've gotten to know him. People who see Avi for the first time might just go by the label. They could miss out on a nice friendship.

So let's not judge people because they seem different on the outside. On the inside, they are probably the same as you and me. Getting to know people who are different and unique helps you appreciate them. You can make some new friends, and you can learn something. That's why our differences make us special. **EP**

"Family is very important," writes Aaron's mom, Sara, "and a great source of support." Last year at Passover, the Wolfson children gathered for a group shot: (Clockwise, from left) Avi, 6; cousins Alex, 13, Rebecca, 16, and Michael, 15; Aaron, 10; cousin Havi, 18, and sister Naomi, 8.

Mom's Turn

Two words sum up what it's like to raise Avi—roller coaster! There are many "downs," such as hospitalizations and loss of skills, and many "ups," like watching Avi perform with classmates in a musical and hearing his hearty laughter. Doug and I have been on this roller coaster ride for seven years. To think we used to joke about hating that particular amusement park ride—how funny and unpredictable life can be!

It was Aaron's own decision to make Avi the subject for his speech. We are proud that Aaron has made Avi a big part of his life. Aaron has taught his friends how special younger brothers can be.

—Sara Wolfson

Aaron Wolfson, a sixth grader at Rockbrook Elementary School, gave this speech last year in a contest entitled, "Celebrate Our Differences." Aaron, 11, lives in Omaha, Nebraska, with his parents, Sara and Doug, brother Avi, 6, and sister Naomi, 9. He enjoys reading and sports, and would like to be a computer programmer.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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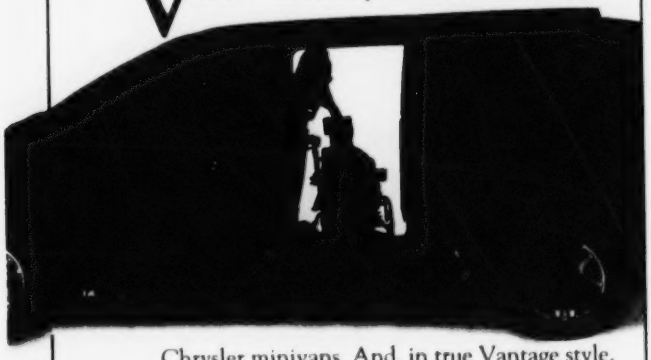

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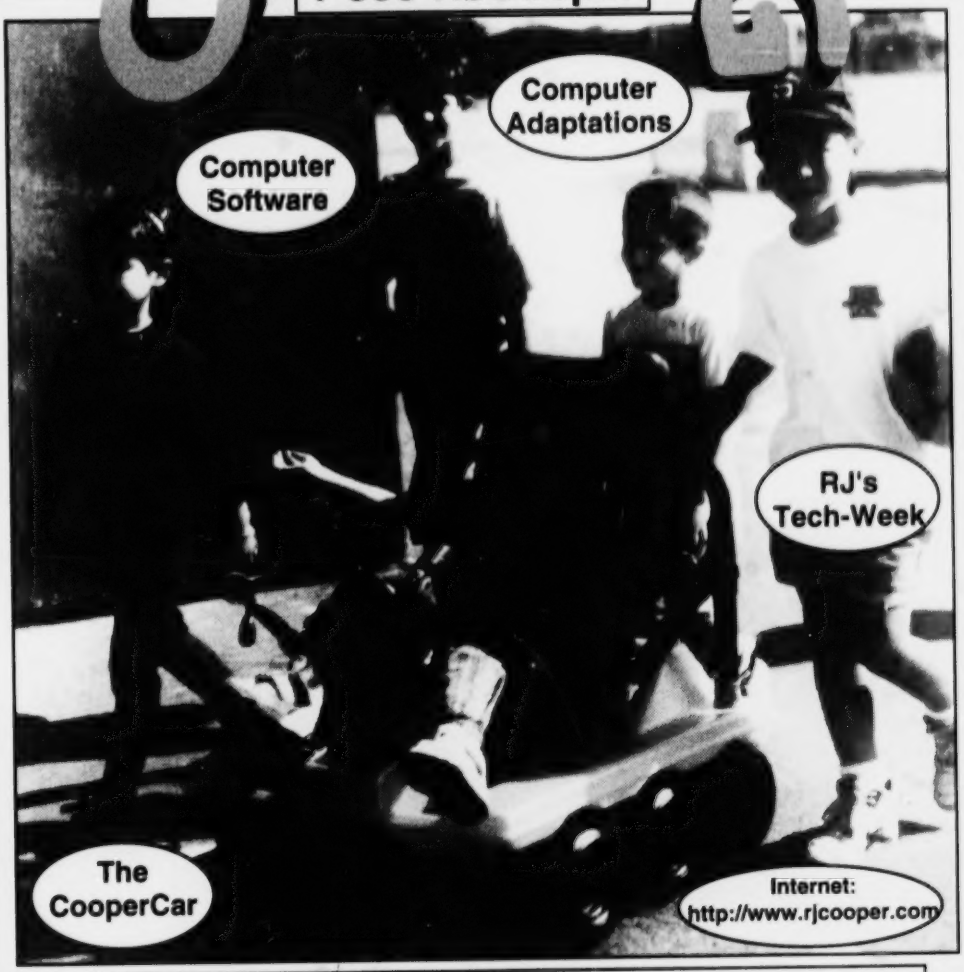

Taylor G, of California, driving the CooperCar with friends

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GENERAL INFO

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RJ's story: During my 3 years of Electrical Engineering (w/digital emphasis) at the University of Utah, I started working with special students at local schools in and around Salt Lake City. I realized that not many R & D people were working with materials for persons with severe disabilities. I began researching, and eventually developing materials that responded to requests of spec. ed. teachers, speech/language pathologists, and professionals that I began networking with around the world.

I moved to CA in 1986 and finished my B.A. in Developmental Psychology, while continuing my research, this time at RH Dana Exceptional Needs Facility in Dana Point. At the same time, I began writing my column for the internationally recognized publication, Closing The Gap.

I started, and continue, to make materials that are requested by others, many that know more about needs than myself. I research & develop these materials in actual settings, with actual people, for professionals and parents that have shown a belief in my work.

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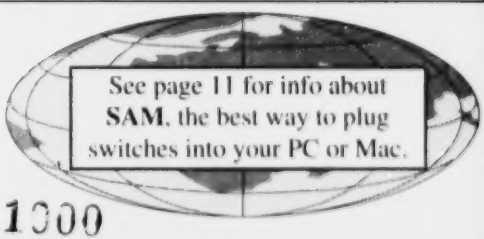


See page 11 for info about **SAM**, the best way to plug switches into your PC or Mac.

Turn-Talking

Availability: Mac & Windows - ***now!***

I invented this concept while working with a little lady named Katie from CA. She knows cause/effect, and I wanted her to be able to interact appropriately in a conversation.

Turn-Talking takes the non-verbal person that needs conversation, on a guided tour of taking turns to talk (like turn-taking, only talking!). A supervisor writes a script, and has a person, close in age to the *talker*, record the *talker's* phrases. Turn-Talking then conducts that conversation.

As with all my newer software, you customize Turn-Talking by writing the scripts, and doing the recording. You can even import your own pictures to represent the Turn-Talkers, or use the provided ones.

Find The Buttons

I wrote Find the Buttons specifically for Jimmy V of NJ. His mom, Harriet, called and we brainstormed this program, and voila, here it is! Basically, this is the only program I know of that teaches a young blind child about graphical user interfaces (GUI). There are 10 buttons you can size and move. As you pass over one, a customized indicator sound is heard. As you leave one, another sound is heard. Whenever you're in the 'margins', where there is no buttons, then another sound is heard. In this manner, auditory feedback always indicates the movements of the mouse. You then click on the button you want, yielding a more detailed sound.

Availability: Mac & Windows - ***now!***

You can record the button indicators and the button sounds yourself. In fact, it works best that way. I provide some starter screens but you'll have more fun and variety if you do the recording. You can tell a story, have funny sounds; the possibilities are limitless.

The Switch Progressions

Adult, Teenage, *or* Children's *(choose one)*
These disks use cartoon-like simulations about real life to start learners with cause/effect and *move* them to timed, purposeful interactions. Graphics are age-appropriate. And you have complete control over how the learner interacts, as with ***all*** of our software!

Availability: Apple II: all of them - now; Mac & Windows: Adult CD - spring, 96
Mac & Windows: Children's & Teenage - now!!
Works with: keyboard, switch, or TouchWindow, or mouseclick

*The Switch Progressions are some of the only software (we know of) that help to teach "**wait!**"*

Spell-A-Word or 2+2

These large-print, early academic programs (available separately) are for beginning to advanced letter and number users. Both disks use an *errorless* learning method. Spell-A-Word works on identification, spelling, & word recognition (for reading). 2+2 works on early arithmetic problems. Both have drill and test modes, which **you** can set.

These disks are designed for you to **easily** enter lists of spelling words, or arithmetic problems (like 2+2=4), for the learner to practice and be tested on.

Availability: ***All - now!!***
Works with: keyboard, any device capable of producing keystrokes, or **switch**.

Early & Advanced Switch Games

Our biggest seller, and our oldest product. This broad variety of switch games is a collection of 19 activities ranging from cause & effect, through following directions, matching, all the way up to using the switch to make a funny face (and print out). And now it's been upgraded for Mac & Windows; it's bigger and better than ever!

Availability: All - ***now!!***
Works with: keyboard, switch, TouchWindow

WakerShaker

During my 11 years of work with persons that have severe cognitive understanding, I have searched for the ultimate cause/effect device. I created it with the CooperCar, **but** WakerShaker (the white object on the right) is a close second. It is is far more convenient, not to mention, far less expensive. Do not take WakerShaker lightly. Yes, **it's a simple switch modified massager** (vibration device), but you simply will not get better, quicker results about what a switch can ***do***. That, after all, is what you're trying to teach with cause/effect training. Besides, WakerShaker is fun! If you are working with a person that needs to understand the ***power*** of a switch, you need WakerShaker. I wouldn't say it, unless I felt I really *knew*!

WakerShaker is $50.
Add $20 for a simple switch as pictured, or use any switch you have.
(Actual WakerShaker may differ slightly from picture)

101 Animations

Here's a simple cause and effect activity that simply puts a large and loud animation (non-age-specific cartoon) on the screen with every switch activation. How many animations? 101, of course!

Availability:
Mac and Windows - ***now***
Works with:
switch, TouchWindow

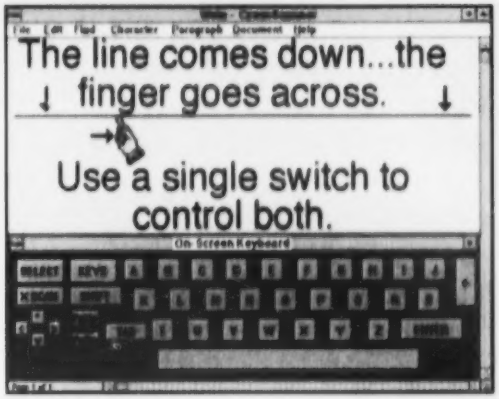
RadSounds

I wanted the ultimate musical cause/effect music program, totally appropropriate for all ages, but really targeted at teenagers. There's plenty of break dancing on the screen and the music is RADICAL. This disk is usable at a slightly higher than cause/ effect level also and comes with a variety of songs. The 3 modes let you target cause/effect or allow the user to be the DJ.

Availability: IIgs, Mac (20 songs), Windows (10 songs) - ***now***
Works with: switch, mouseclick.
Windows requires a sound card. Good, external speakers recommended for all!

CrossScanner

CrossScanner is a universal way to run all *non-adapted* software by single switch, or any pointing device. Using a single switch plugged into any device capable of producing a mouse-click, such as SAM, or any device that can *be* the mouse, such as a mouse, joystick, trackball, and several others, the user is able to perform mouse moves and clicks, double clicks, drags, operate menu's and enter text. The user interface is incredibly intuitive. All operation is supervisor-controllable to fine tune CrossScanner to the needs of the user.



Availability: Mac and Windows - ***now***

Works with: any device capable of being the mouse-click (single switch mode) or any pointing device (direct select)

The first click starts the lineScan down the screen. The next click stops the line when it gets to the user's desired vertical point. If DoubleClick, Drag, or Text Entry is active, an iconWindow pops up for the user to select between with the fingerScan. The final click tells the computer to move the cursor to that point and perform the chosen function.

Biggy

Finally, BIG cursors for your Macintosh! This control panel allows you to choose from between 4 really large cursors, that work in/with any program. Two of them, actual size, are at the right.

Availability: Mac only - now! Only $29!

The CooperCar

Accept no imitations! Ask for it by name!

Our CooperCar Conversion Kit adapts this 'kid-car' so that even the most disabled child can drive in safety...using whatever ability he/she has: wiggle a toe, move a finger, rotate his/her head...anything!

The CooperCar consists of:

1. The BOSS vehicle power base - $400; with a Premium Charger. We only have a limited number of BOSSes left so you best hurry!

2. The CooperCar Conversion Kit, which is the heart of The CooperCar, consists of our computerized electronics, joystick, switch, bungies, & video - $700. Use your own adaptive seat, switches, and mounting, if you have.

3. The *wireless* remote safety override - $150. Useful for safety (obviously), but also great for turn instruction and assistance. Wired over-rides are included with the normal kit.

4. The Magic Arm is an incredibly moveable arm which allows you to position the joystick/switch wherever it needs to be, and it stays there - $200.

5. Footrests (specify S,M,L) - $125.

Please understand that **you take full responsibility** for operation and safety of The CooperCar. Because it is a kit, **we cannot be held liable for the manner in which you've assembled and are operating the vehicle**.

The CooperCar is very easy to adapt. Just follow the video that comes with your Conversion Kit. Basically you're just plugging in 6 wires; no soldering; no cutting!

The CooperCar has Speed, Acceleration, and Time controls (Time is for those that can't *maintain* contact with their controller, the CooperCar will travel in the chosen direction for a certain Time). There are switch inputs for the 4 directions, and a **proportional joystick** input. The joystick can also be put into *Pull=Forward* mode.

RJ's Tech-Week

Combine Technology and Family Fun...

...during a week of exploration and learning!

Haven't you wished, time and again, that you could spend time watching, learning, and interacting with someone like RJ Cooper while he works, personally, with your special needs family member? Hundreds of you have seen RJ in action, or spoken with him, and expressed this exact desire.

Many parents and professionals feel that RJ may be the best in the world for stimulating and motivating persons with severe to profound disabilities, either physical and/or cognitive.

Also, through interacting with hundreds of family members, RJ is uniquely qualified to implement just about any adaptive technology with the special needs family member **and** teach other family members about that technology and the adaptations necessary!

Sessions take place in the morning so the afternoons are free for such popular attractions as Disneyland, Sea World, Knott's Berry Farm, Los Angeles, San Diego, whale watching (in season), ocean fishing, beach-going, and a variety of other activities, all within 1 hour. There are even options for taking the other kids on excursions while the parents and special needs family member are intensely exploring technology options, hands-on! Or, RJ will structure the sessions so that <u>all</u> family members participate in the technology fun.

Each month, **<u>year-round</u>**, RJ will give 2 families the opportunity to come to sunny southern California, with their entire families (yes, your able-bodied kids also!). You will work with RJ, personally, for 2 hours each day for 4 days. The first hour will be with your family members that need to know more about technology, learning exactly how to operate the specific software and hardware necessary to cultivate growth in your special needs family member (even The CooperCar, when appropriate!). The second hour will focus on interaction, between RJ and your special needs family member, you, and any other family members you wish to be involved. RJ will try different software and hardware ideas, attempting to stimulate significant changes in their behavior, learning, communication, and understanding.

You will leave RJ's Tech Week with a new motivation and knowledge of the software, hardware, methods, and materials necessary to really get things going back home.

Several lodging packages are available, but space is very limited so...

Call or write for a specific brochure on RJ's Tech Week!

Lectures/Workshops

I have lectured at over 500 facilities, on 3 continents. My expertise ranges from severe/profound to mild MR or LD. Most of my experience is with children, but many recognize my research & developments with adults also.

Lectures/workshops take a hot-seat, hands-on approach, where members of the audience are called upon to demonstrate on-stage equipment during the workshop. For each period of lecture, I request an equal time working hands-on with individual learners and staff, demonstrating and exploring methods and materials, and adding to everyone's knowledge base, including my own.

I'd like to really *connect* with you and your learners!

Topics include:

Adaptive Mobility for Young Children: Secrets of The CooperCar

Early Communication Skills and Augmentative Communication Training

Cause & Effect Software & Hardware: Let's Really Understand it!

Making the Most of RJ's Software

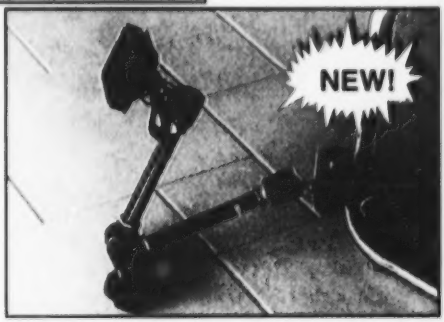
Making Your Most Challenging Learners **Successful**

Multimedia and Special Needs Software Authoring

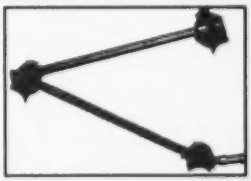
Please call or write for fees and scheduling.

The Magic Arm System

This arm has changed the way I work with switches. Pictured here with one of our simple switches, the Magic Arm attaches securely to just about anything: wheelchair tubing, tables, the CooperCar rollbar, you name it! The dial at the *elbow* tightens all three joints: the one at the base, the elbow, and the switch end. And when it's tight, it REALLY holds everything in perfect place. This arm is **infinitely** adjustable, and ***stays*** where you put it. Talk about perfect positioning...YES! You can attach any switch, joystick, or SAM to its end-plate.



$200 as pictured above



I realize the cost of the 'real' Magic Arm may be prohibitive, so I am also making available its little *brother*, the Articulated Arm. It, also, is infinitely flexible, but has **three** knobs to tighten, versus one, and is not quite as strong as the Magic Arm. $100 with Super Clamp.

Switch-Adapted Mouse

Now you can plug your switch(es) into our Switch-Adapted Mouse (**SAM**) device for your PC or Mac for a *variety* of purposes!

1) Operate all special needs software that can be operated by a mouseclick (like ours!) or simple keystroke(s).

2) Access all *regular* software, like that from any computer store! The switch-user does all the clicking of the mouse, through SAM, while **you** move it. This turns any computer activity into great cooperative fun.

3) Allow a person with gross-motor hand (or fine-motor head) control to move the mouse, and do the clicking.

You simply plug SAM where your current mouse is, and plug your switch(es) into SAM. A switch plugged into one of SAM's 3 switch inputs acts as the corresponding button, function (click, double click), or defined keystroke[s]. The middle button is a useful drag-lock.

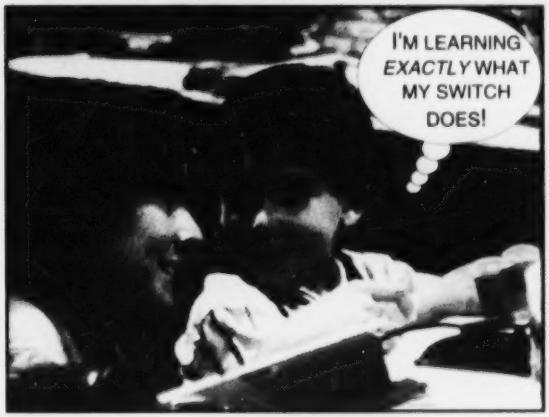
I also make SAM as a joystick. It also has a click, double click, and drag switch inputs. I've seen this joystick really change lives! When you push the stick, the cursor does **not** go flying, no matter what the user does. It simply moves in that direction at a given speed, controllable by the supervisor from a switch underneath. I recommend mounting SAM to a CooperCar arm, for optimal positioning.

PC or Mac - $120 Add $20 for a simple switch.

PC users - you **MUST** specify serial (9 pin) or PS/2 (round) connector for the SAM-TRACKball. SAM-JOYstick plugs into your joystick port, usually found on your sound card.

(Remember, please add 10% for shipping and handling)

BUILD-A-SCENE



Designed to teach 1-1 correspondence (between cause and effect), this disk uses large, colorful graphics, auditory feedback, and plenty of high quality digitized speech. Each activation adds another part of a scene to the picture. You can take a trip to the Beach, Breakfast table, Park, or Zoo.

Availability: Apple II-now; Mac & Windows - winter, 95/96.
Works with: keyboard, switch, Touchwindow

The Human Being Machine

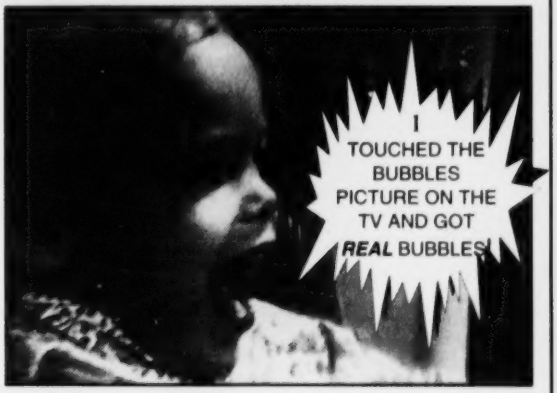
A recreational disk that you can also use to teach about the body. The learner scans and chooses body parts, from a fun selection, to *assemble* a human being of their choosing. You can then print out the body or face in several ways.

Peggy Morrison, a speech/ language pathologist friend of ours originally authored **BodyBuilder**. We combined this with **Looney Goonies**, a face building program, that Bryan (see top of page 2) wrote years ago. RJ then put his special touches on them while adding high quality speech, talking menus, etc.

Availability: Apple - now; Mac & Windows - winter, 95/96.
Works with: keyboard, switch, TouchWindow.

Point To Pictures (PTP for TouchWindow or pointing devices)
Picture Scanner (PS for switches), and the *RJ ClipArt Disks*

To learn about, and use pictures for communication, these are some of the only materials available that focus on real, available, *things*. Using the communication or 'You Find' modes, **you** choose groups of pictures with which the learner will interact, from the:



RJ ClipArt Disks (these each require either PTP or PS): Letters, Numbers, Shapes, Toys & Adult Appliances, Mayer-Johnson (MJ) Picture Communication Symbols (PCS), Things (misc. immediate reinforceables)

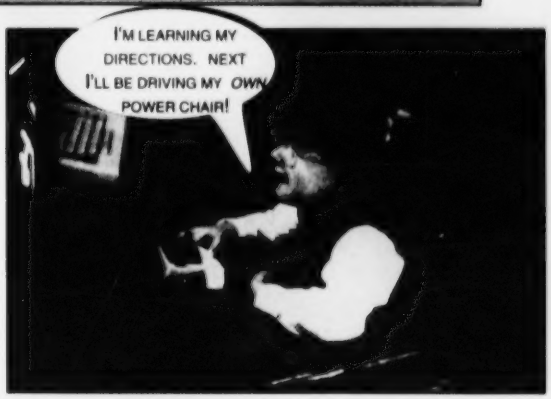
* To present early academics at the most *basic* level, use PTP or PS with the Letters, Numbers, or Shapes RJ ClipArt Disks. **You** choose, from a great variety, which concepts the learner practices.

Availability: Apple II - all disks now available; Mac & Windows - winter '95-96
Works with: PTP can use the TouchWindow (on the monitor or horizontally, on a surface), Power Pad, or any other touchpad that can produce the numbers 1-9 (like a Concept, Intellikeys, or Unicorn alternative keyboard). PS uses 1 or 2 switches.

Remember, with PTP and PS you can author **specific** lessons for **your** learner, choosing only those pictures that are personally motivating for him/her, from the included or optional RJ ClipArt disks. Each item on a ClipArt disk has high quality *digitized* speech, and colorful animations designed to be functional and fun!

JOYSTICK TRAINER

Practicing joystick skills by computer is a lot safer than experimenting with a power chair! This disk starts at a very early motor and cognitive level, and progresses thru 9 activities of increasing challenge. We know of no other program that trains joystick skills like this one.



Availability: Apple-now; Mac and Windows - summer, 95
Works with: SAM-Joystick (see page 11)

If you look at page 11, you will see my new SAM joystick, which controls the cursor (arrow) just like a mouse! With this great device, you are able to operate all *regular* software. There are many simple regular titles that really lend themselves to early, intermediate, and advanced joystick control. You may use any of these commercial products with SAM-Joystick. Please call for more details. I'd love to discuss this with you and get your feedback.

Internet: Point your browser to <http://www.rjcooper.com> and visit our pages on the World Wide Web! Be sure to download RJ's Movie Viewer so you can view the programs available there. It's almost like being in an arcade. I'll be working on some pseudo-Virtual Reality navigation through my pages, so I hope I see you there!

The way that I prioritize my developments is by feedback from you. If you want a project completed faster, don't be afraid to bug me (call or write). When I know a product is really needed, I work harder and I prioritize that project. So take advantage of this direct link to a developer and stay in touch!

RJ's Demo Order Form

Please **check computer type:**

Windows__ Mac__ Apple II type (includes LC w/IIe card)__

Please verify your name/address on the bottom back of this form.

Find The Buttons __ Turn-Talking __ 101 Animations __
RadSounds __ CrossScanner __ Spell-A-Word __
Early & Advanced Switch Games __ 2+2 __
Switch Progressions: Children's __ Teenage __ Adult __
Build-A-Scene __ Joystick Trainer __ The Human Being Machine __

Point To Pictures (PTP) __ Picture Scanner (PS) __
RJ ClipArt Disks: (These each require PTP or PS; see page 13)
Mayer-Johnson PCS __ Things __ Toys & Adult Appliances __
Letters __ Numbers __ Shapes __

Please note: if the disk you requested is not ready yet, on the computer type you've requested, we will send it upon completion.

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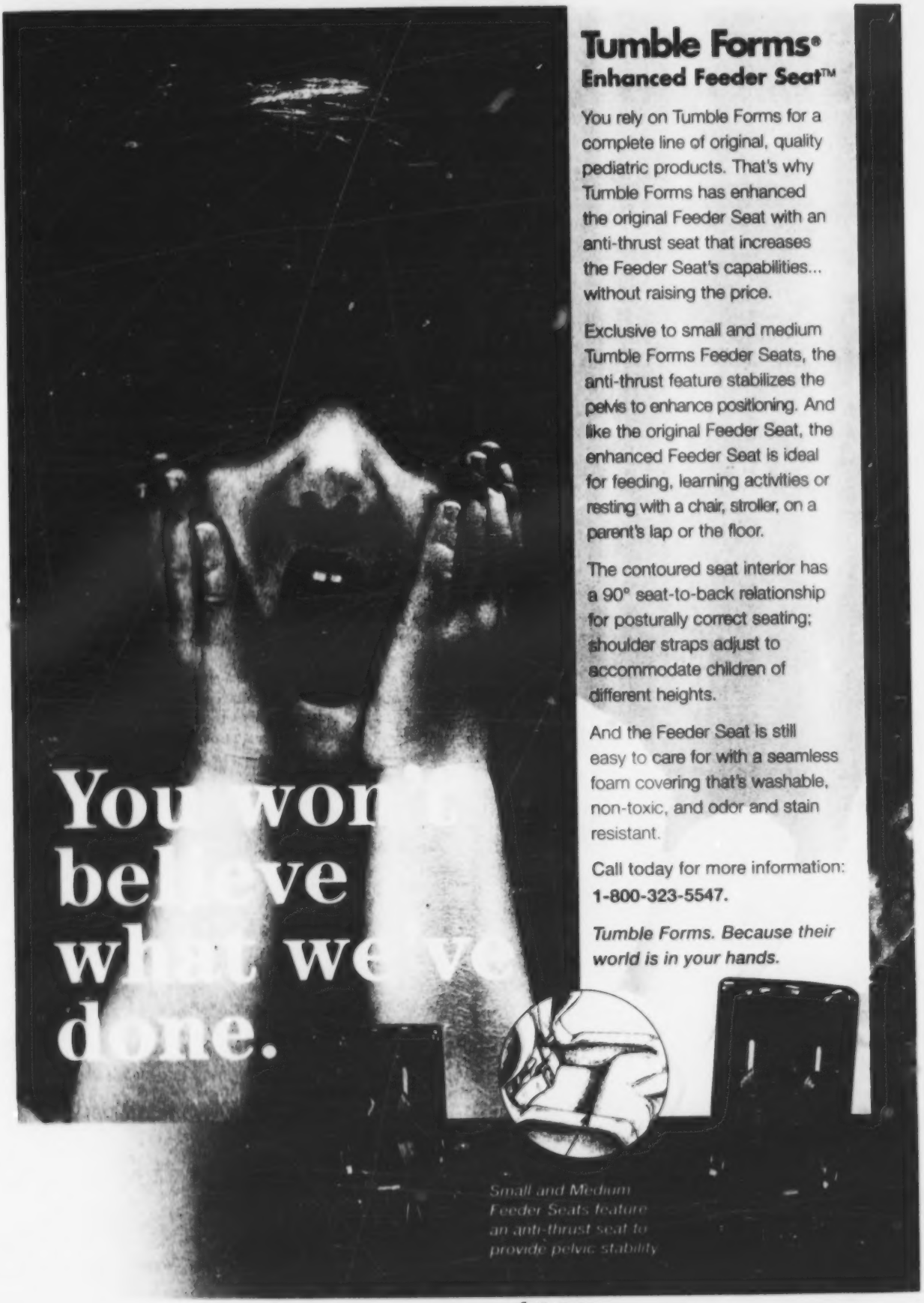

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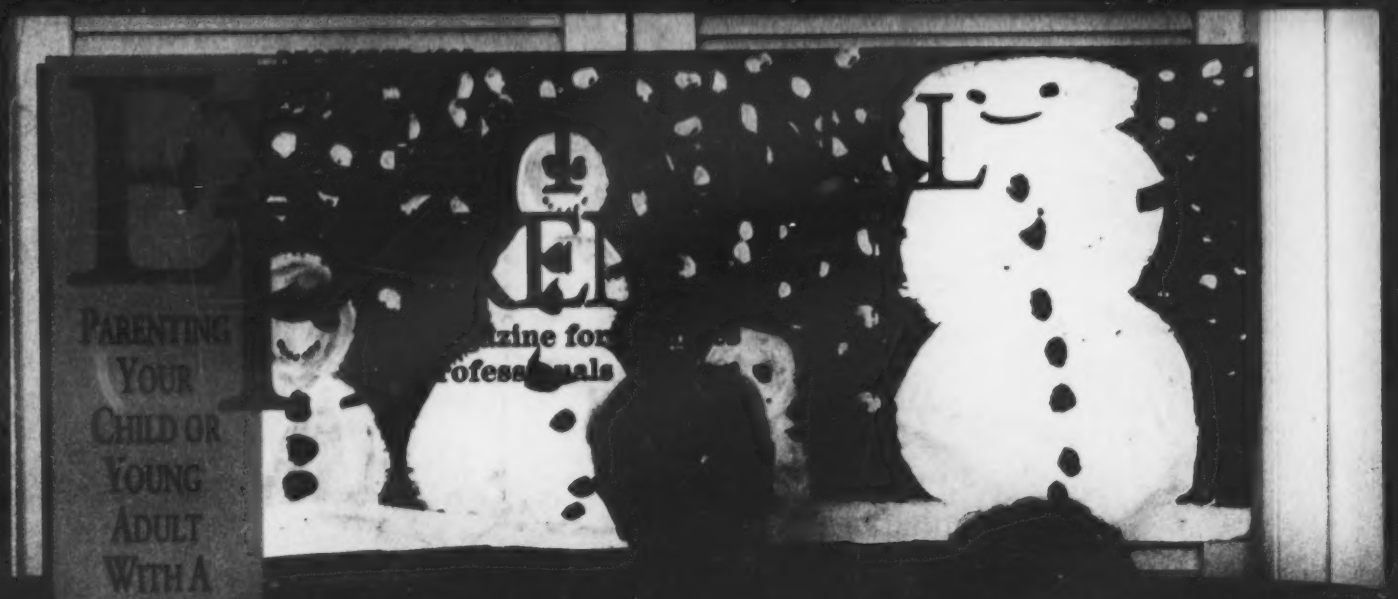

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1016

MOVE International

GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

MARKUS SMITH
Working toward a dream

Markus' physical therapist, Darron Veh, called me in October of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral palsy. We had "tried" many different things to improve his motor abilities, but Markus had made little progress in the last several years. Markus could stand in a prone stander, but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron introduced us to MOVE and the Gait Trainer and Mobile Stander. Markus loved the stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Gait Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his every little success. His self confidence began to grow.

A year ago, Markus told a doctor, "My greatest hope is to walk someday." He was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Gait Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said, "I love having a desk like the other kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

–Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh, P.T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.

For more information, contact:

MOVE International,

City Center, 1300 17th St.,

Bakersfield, CA 93301;

(800) 397-6683

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Call **800-374-3866**

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FOR PEOPLE WITH DISABILITIES

PO BOX 901, RIFTON, NY 12471

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Circle #41

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EXCEPTIONAL PARENT
PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY
Since1971
The Magazine for Families and Professionals
DECEMBER 1995 VOL. 25, ISSUE 12

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Cover: "Not a creature was stirring..." Each year, "Papa" Norman Janson reads his four grandchildren a story on Christmas Eve; it helps them pass the time between eating dinner and opening their gifts! Surrounding Papa are (from left) Ellen Moore, 4, Tommy Moore, 11, "Nonie" Jackie Janson, Stephen Moore, 2, and Jimmy Moore, 13. Tommy, who has moderate mental retardation, loves spending time with Papa and Nonie—as does the whole family. Read about the special bond between Tommy and his grandparents in Susan Moore's Readers Talk article, "Papa and Nonie."

Tommy, Ellen, Stephen and Jimmy live with their parents, Susan and James, in Black Jack, Missouri. Papa and Nonie live about a half hour away in Normandy, Missouri. Photo: Dean Benge/Shutterbug Photos.

BPA

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EDITOR'S DESK

Happy Holidays!

As we come to the end of a busy and exciting year, all of us at EXCEPTIONAL PARENT would like to extend our best holiday wishes to all our readers. This issue is filled with moving letters and stories from our most reliable resources for editorial wisdom—parents. While more and more professionals are becoming regular readers of the magazine, it is the energy, dedication and feedback of parents that has always sustained us.

STANLEY D. KLEIN, PH.D.

Families

Readers Talk continues to be a wonderful resource, in which many readers have participated. In this issue, as in so many others, the *Readers Talk* stories and other reader articles inspire us—their creative efforts energize other readers—parents, professionals and people with disabilities.

Readers' stories and letters often relate feelings of being "cheated" and angry when faced with the unexpected responsibilities of parenting a child with disabilities or special health care needs. Later, parents may feel guilty about these initial reactions. Perhaps that guilt will diminish with the knowledge that such difficult feelings and thoughts are normal, healthy, mature and human reactions for parents, grandparents, siblings and other family members. Although reading some of these letters and stories can raise troubling feelings—no matter how much "experience" any reader may have—sharing these feelings can be empowering. Together we can validate the challenges and joys we regularly confront; we can cheer each other on throughout every year.

The love of a family is a unique "natural" resource, growing even as it is shared. People concerned about modern-day "family values" would do well to read about the heroes of this issue—grandparents, cousins and other members of "extended" families. Although families may be separated by emotional or geographic distance, family members can find ways to provide love and support to children with disabilities and their parents.

We were especially pleased to discover support groups for grandparents at PACER, a Parent Training and Information center in Minneapolis, Minnesota. In reaching out to grandparents, PACER breaks new ground and provides a model for other communities. We are interested in learning about other programs for grandparents and great-grandparents, including those who are geographically separated from their families.

Words and Worries from Washington

It is hard to know what Congress will do next regarding issues such as the funding of Medicaid or the reauthorization of the Individuals with Disabilities Education Act (IDEA). We are therefore pleased to share Senator Bill Frist's (R-TN) remarks on the progress of the reauthorization.

During the second half of this year, we have presented several articles from key Administration and Congressional leaders. We will continue our efforts in 1996, confident that before Election Day next November, we will be able to publish what the major Presidential candidates have to say about topics that are relevant to people with disabilities and their families—just as we have done each election year since 1972.

Estate Planning

At a time of year when we take stock of our lives and cautiously look to the future, we are initiating a new regular department on estate planning. We are eager for questions from readers that can be addressed through this new department.

Our Silver Anniversary

In 1996, EXCEPTIONAL PARENT will be 25 years old! While it is unlikely we will find a way to mail each reader a piece of birthday cake, each issue during the year will celebrate this milestone—beginning in January with our Annual Resource Guide, the most comprehensive in our history. We are immersed in gathering information for the Guide and making sure it is presented accurately. We have already contacted hundreds of groups and want to thank everyone involved for their helpful participation.

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Parenting Your Child or Young Adult With a Disability
Since 1971
The Magazine for Families and Professionals

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LETTERS

The Friendly Skies

Congratulations on your publication of the article entitled "The Friendly Skies" (August 1995). The public needs to learn about the host of available charitable, long-distance air medical transport options.

Unfortunately, the sidebar listed only some of the nearly 30 volunteer pilot organizations providing this type of service. And because the article focused only on those organizations providing services to medically stable individuals, readers might not realize there are at least three charitable air ambulance organizations that provide in-flight medical support.

Actually, there is no practical way you could mention all organizations—nor in any way keep up with where they will fly and under what circumstances. That is why the Air Care Alliance, an umbrella organization committed to assisting and publicizing all known charitable air medical organizations, maintains a 24-hour, toll-free hotline (800/296-1217). One call to this number can provide referrals to all known, appropriate forms of medical air transport.

Thanks again for running this story. One of our greatest challenges is getting the word out to those who need these services.

Edward R. Boyer
Executive Vice President
Air Care Alliance
Manassas, Virginia

Respecting Choices

I was alarmed and dismayed by the article "Common Questions About Inclusion" (September 1995). Authors Dorothy Kerzner Lipsky and Alan Gartner claim strong, positive support for inclusion from a few favorable research studies, but, in my opinion, the authors raise many more questions than they answer. How can any study make a generalization about what is appropriate for all children when disabilities vary so widely? Are these studies even relevant? Do we parents need studies to tell us whether inclusion works or doesn't work for our children?

Some of us have children who are medically fragile. Others have children whose nervous systems cannot handle noisy environments or whose academic progress requires specialized instruction. Special education was created to meet special needs such as these. Let's not throw out the baby with the bath water. Of course, full inclusion may be the best option for some children, but parents must unite against it becoming the only option left for any child.

Last year, a teacher in our school district taught a workshop entitled "Making Inclusion Work for All Children." I'm sure this woman had no idea that what her workshop proposed was a violation of the Individuals with Disabilities Education Act (IDEA), which guarantees that a full continuum of placement options be available so each child can be provided with an Individual Education Plan (IEP) based on his or her special needs. Unfortunately, full inclusion seems to be a political movement driven by people who mistakenly see it as an issue of

continued on page 6

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PRODUCT NEWS

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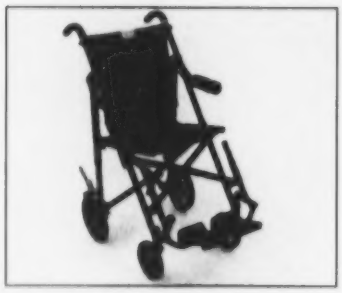

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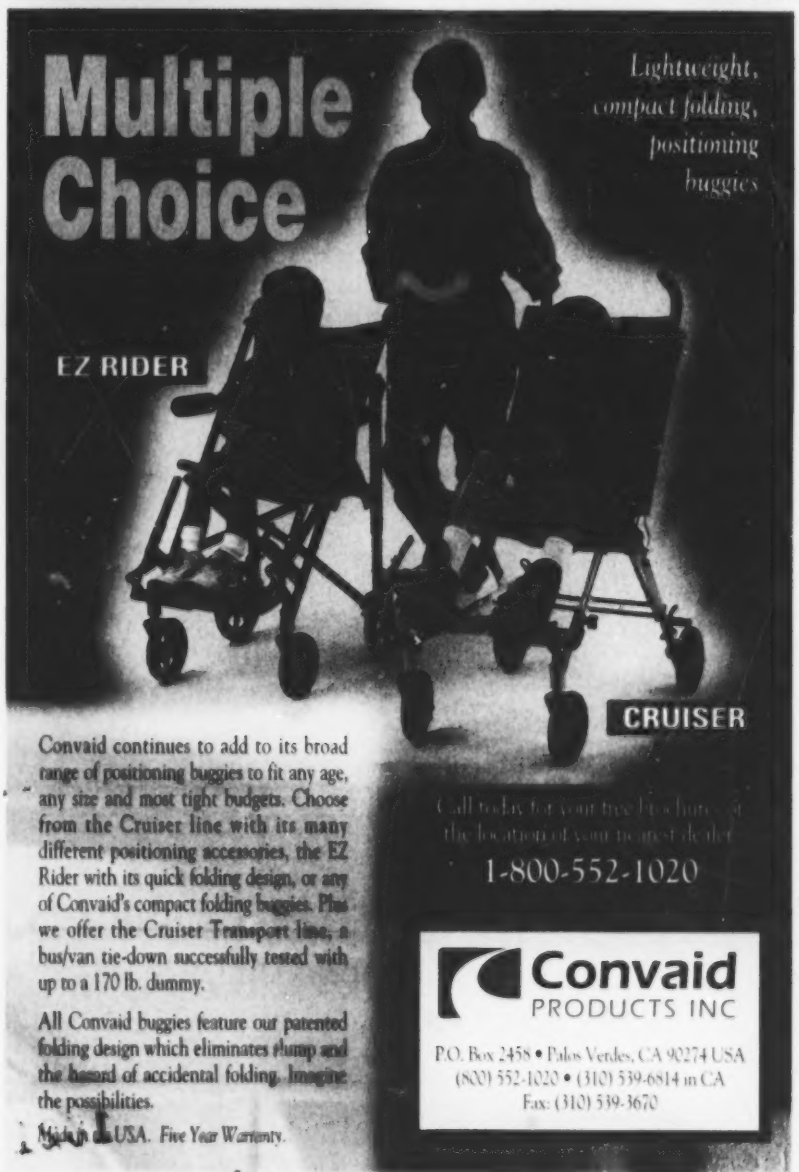
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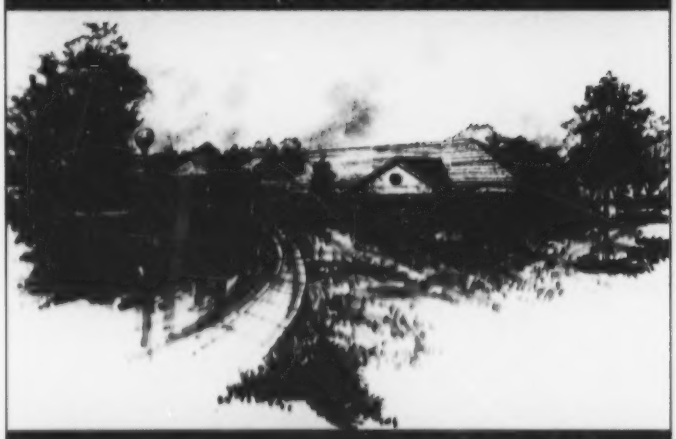

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Photo courtesy of Madeline McCullough and Ric Wolford

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LETTERS

continued from page 4

civil rights, rather than education.

Don't get me wrong; I support full inclusion for any child with disabilities who can learn in a regular education classroom with appropriate supports. I wish with all my heart my child was one of those children!

My son, Andrew, who has pervasive developmental disorder (PDD), is an "included person" in our community, in our family and at his school, where I have struggled to obtain a special program for him in a school district with a "one-size-fits-all" approach to education.

Andrew now spends 70 percent of his time in a self-contained classroom and the rest of the time with a regular first grade class. Full inclusion is the most restrictive environment for my son. Often, in his regular classroom, Andrew becomes extremely anxious when he cannot understand the material being presented. When overwhelmed, he "tunes out" by talking loudly to himself, flapping his hands or reaching out aggressively at other children. "Escape behaviors," as they are commonly called by teachers, mean exactly that—"get me out of here!"

In contrast, Andrew happily joins "circle time" in his self-contained classroom. He enthusiastically participates in a calendar activity, sings songs he knows and works on identifying his full name written on a card. We know that our child's integration into a regular classroom must be very gradual and based on his abilities, not on administrators' desires to cut costs. Some children may have the potential to move out of a special education setting only if we address their special needs early and aggressively.

Inclusion does not have to be an either-or situation. Many schools are trying progressive approaches such as team-teaching, which combines special education and regular education classes, or reverse mainstreaming, in which regular education students integrate special classrooms. These and other creative approaches can make special education students an integral part of regular school life without forcing full inclusion on everyone.

Authors Gartner and Lipsky report that a 1995 study of inclusive education programs done by their center, the National Center on Education Restructuring and Inclusion (NCERI) at The City University of New York, demonstrates that "...school districts across the country are successfully educating students with all types of disabilities—at all levels of severity—in inclusive classrooms."

I would ask these authors to think about the audience for whom they are writing: We are the parents in the trenches fighting battles with insensitive systems. We are fully capable of assessing our children's programs. We don't need a study to tell us that inclusion is working so we can go back to sleep and put our trust in school boards and administrators.

Authors Gartner and Lipsky write that parents should make decisions about inclusion based on "...the law, an understanding of relevant research and the family's values."

I would reply by saying that this is not a "family values" issue. Or maybe it is. In our family we value respect for life and respect for the individual needs and differences of every human being. I want for my son what all parents want for their children—that he reaches his full potential, whatever that potential may be.

J.U., California

■ I just want to commend EXCEPTIONAL PARENT for impartially presenting both sides of such complicated and emotionally-charged issues as inclusion and residential care. You understand that no single answer is right for every child and family.

Take inclusion, for example—inclusion is great in theory, but in real life, it is not always the best alternative. You can't say "all kids with disabilities" any more than you can say "all people with epilepsy," "all women" or "all whites." We are all individuals and should be treated as such.

I applaud the decision of Jill Chester-Haney of Ontario, California ("A Lesson from the 'Inclusion People,'" September 1995) to place her child in the school she believes best meets his needs. Jill knows what is best for her child, and no one should challenge her wisdom. Inclusion should always be available, but it is not always right.

D.E., California

■ We had submitted a *Readers Talk* piece for the September issue entitled "The Politics of Inclusion: One Family's Journey." Although we were disappointed that our story was not published, we were very pleased with that issue's coverage of topics related to education. The articles were excellent and the *Readers Talk* pieces provided a balanced view of inclusion.

We are currently fighting the New York City Board of Education to get inclusion for our son, so we really appreciate your coverage of this topic. We are sure that the September issue of the magazine has helped parents become more knowledgeable. I know it has given those of us "in the heat of the battle" the strength to pursue our vision, knowing that we are not alone in the struggle.

L.L. & S.K., New York

"Genetic Counseling" Clarification

I was pleased to be interviewed for "Genetic Counseling: Part Two" (September 1995). The article concerns a subject about which it is increasingly important to be well-informed, as the boundaries of genetic knowledge expand rapidly. However, I would like to clarify and correct my comments as quoted.

I was disappointed that the article omitted the essential fact that I am the proud parent of a seven-year-old daughter with Down syndrome. Having a child with Down syndrome has led me to reflect on the meaning and value of her life and the lives of others who can be said to have some sort of genetic "defect." My parenting experiences have made a significant difference in my perspective on these issues. My professional experiences with other parents and chil-

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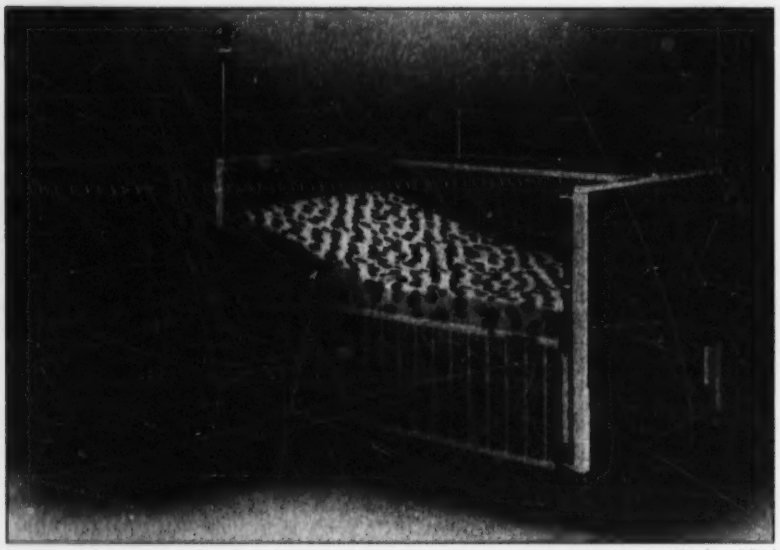

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dren also inform my views on the importance of complete and accurate information in genetic counseling.

I am concerned that my statements, as printed, appear unduly critical of those engaged in genetic counseling. Although I believe that expectant parents frequently receive excessively negative and incomplete information, I did not intend to imply that those in the field are uniformly or deliberately negligent. My statement about the information people are given regarding the risk of and prognosis for heart defects in children with Down syndrome appears slanted because the word "often" appears in the wrong sentence. In fact, I said, "People are told that 30 to 40 percent of children with Down syndrome will have a heart defect, which is accurate. But they often are not told that, now, most of these heart problems are correctable."

I was trying to make the point that what is unsaid can be as important as what is said. While it should be assumed that any professional who provides genetic counseling is well-versed in the scientific facts concerning risk, diagnosis and prognosis, parents have the right to hear more, especially that which is encouraging and affirming. Much of what is most significant to parents—the "prognosis" for their child's future life—cannot be reduced to numbers and facts. Those of us who live with and love children with disabilities have learned that many things that would once have seemed unthinkable or unbearable—a diagnosis, a procedure or an obstacle—can indeed be borne or overcome for the sake of our children. This knowledge comes most surely through personal experience.

Clinicians may need to be more deliberate in their efforts to stay up-to-date not only with medical advances (for example, the availability of successful open heart surgery for previously inoperable defects), but also with the ways in which children and families are living with genetic conditions. Advances in medical care and educational, social and vocational opportunities are constantly changing the expectations and possibilities for babies born with Down syndrome or a host of other conditions. In addition, current research indicates that a child with a disability does *not* inevitably have a negative impact on family functioning; that old belief is mistaken.

Since genetic counselors may not have the opportunity to experience the joy that accompanies a long-awaited first word or the daily good-night kiss of a child with Down syndrome, I believe it is beneficial for them to work closely with parent groups or other resources that can provide this vital perspective to prospective parents faced with a most challenging decision. As genetic research increases the number of conditions that may

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Circle #98

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be identified before birth, there is also an increased need for such collaboration, along with open, informed communication. No one can offer a guarantee on a child's future, but a concerted effort can present a sketch of the possibilities and pitfalls, as well as some tools for adding detail and vigor to the picture.

Susan Morse-Fortier, Massachusetts

Inspired by "Karate Kid"

"The Karate Kid" (*Children's Page*, October 1995) was a very inspiring article. Barry's karate instructor is a beautiful example of the importance of these exceptional human beings in the lives of our special kids.

We live in Costa Rica, where I spent many months looking for a preschool that would accept and appreciate our two-year-old daughter, who has mild spastic diplegia cerebral palsy. Every place I went gave me a different reason for rejecting her.

Finally I found the director of a small Montessori school who not only wanted our daughter, she sought *us* out! This woman is like a hero to me. Janie is thriving in the Montessori school, and her teacher welcomes communication between us in ways that directly benefit our daughter. In these times when many of our children's gains are being threatened, such exemplary people are especially valuable.

B.M., Heredia, Costa Rica

Understanding Enuresis

The article "Understanding Enuresis" (August 1995) should have mentioned that diabetes insipidus, albeit rare, can be a cause of enuresis. An under-diagnosed disease, diabetes insipidus has no cure. If not properly managed, the condition is life-threatening, due to either dehydration or water intoxication.

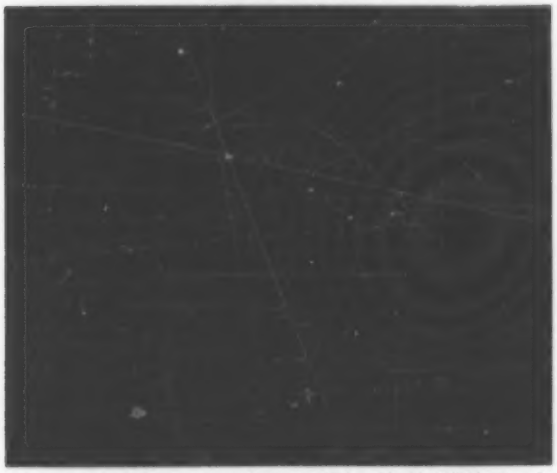
I know this because my seven-year-old son has diabetes insipidus. He is totally deficient in vasopressin (the antidiuretic hormone, or ADH) and arginine, the main amino acid precursor to vasopressin.

I have met many parents whose physicians did not properly diagnose their child or reacted skeptically to a diagnosis made by another physician. The medical community needs to learn more about diabetes insipidus. Diabetes insipidus is not the same thing as insulin-dependent diabetes. And it's not *just* excessive thirst and urination; diabetes insipidus means problems with fatigue, body temperature regulation, behavior, learning and memory. Yes, America, there really is another diabetes!

M.A., Maryland

EDITOR'S NOTE: The Diabetes Insipidus and Related Disorders Network (c/o Beth Perry, 1622 185th St., Creston, IA 50801-8172; 515/782-7838) is an informal network of families and individuals affected by this condition. The network publishes an occasional newsletter and can help parents of children with diabetes insipidus contact one other.

To help a child recover,
we often rely on
some highly qualified
specialists.



When a serious injury or illness brings a child to Health Hill Hospital for rehabilitation, we provide the best specialists possible. Experts in everything from respiratory problems to cerebral palsy to spina bifida to seizure disorders to head injuries to feeding disorders. Under the direction of a physician specializing in pediatric rehabilitation, a therapy program is developed for each child. And always, the team will include a specialist who has a unique role. The child's Mom. Or Dad. Or both. Because we know the importance of involving family in the entire process. And because we're not only preparing children to go home. We're preparing their parents to care for them once they get there. Health Hill Hospital For Children, 2801 Martin Luther King Jr. Drive, Cleveland, OH 44104. 216-721-5400.

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1629

Circle #185

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SEARCH

Leg Braces and Ripped Clothing

My six-year-old daughter, Maria, was born with spina bifida. We live in South America, but we bring Maria to Boston every year to see her doctors.

With leg braces (reciprocating gait orthoses, or RGOs) and a walker, Maria is now walking very well. However, her walking has led to a problem: Maria, who is very fashion-conscious, likes to dress up every day to go to school, but she rips and destroys her clothing when the material gets caught between her braces and the walker.

This probably sounds like an insignificant problem, but Maria doesn't have one piece of clothing that is not ripped. I don't know of any other children in Cali, Colombia who use leg braces and walkers. I would really like to hear from other parents who can share their experiences concerning little girls, dresses, leg braces and walkers. I believe it is very important for parents to be in touch with others who have children with the same kind of disability, so we can share both simple and complicated experiences.

M.R., Cali, Colombia

Langer-Giedion Syndrome

Our 18-month-old son has been diagnosed with Langer-Giedion syndrome (also known as trichorhinophalangeal syndrome, Type II), a rare chromosomal abnormality. Ben has a tiny interstitial rearrangement affecting two bands on chromosome eight.

Ben is a delightful child—bright, funny and loving. He does not appear to have any mental retardation. He was born with some subtle facial differences, which have since "normalized," according to his doctor. His ears are the only exception; both stick out, and one is smaller and missing a fold. Ben also has low muscle tone and is very small for his age (18 pounds at 18 months). He is currently being tested for a suspected mild hearing loss, and we have just discovered the first piece of "bony growth"—another characteristic of this syndrome—on one of his shoulder blades.

We would love to share information and support with other parents of children with this condition.

L.K., Toronto, Canada

EDITOR'S NOTE: The National Foundation for Ectodermal Dysplasias (P.O. Box 114, Mascoutah, IL 62258-0114; 618/566-2020; 618/566-4718, fax) can provide information about Langer-Giedion syndrome and can put you in touch with other families who have children with this condition. (Both types of trichorhinophalangeal syndrome are forms of ectodermal dysplasia.)

Failure to Thrive and Scoliosis

Our youngest daughter, Hannah, is 19 months old. She was born with an extremely rare condition known as Aicardi syndrome, in which the corpus callosum (the band of fibers connecting the two hemispheres of the brain) fails to develop. Only girls are affected by Aicardi syndrome; it is believed that affected males die in utero. The condition involves seizures, visual problems, low muscle tone and moderate to severe mental retardation. Girls with the syndrome are usually non-verbal and very few are mobile. Some have spinal defects; Hannah has severe scoliosis.

We are looking for information on two aspects of Hannah's condition. At this point, Hannah weighs just 15 pounds. She becomes sore after sitting for only a short time because of the lack of fat on her bottom. We can't pick her up by grasping her under the arms; it hurts her because she's so thin. She's been classified as "failure to thrive." Doctors tell us her body does not utilize the nourishment it should from her food. She's always been a poor eater and until about six months ago, refused all solid foods. She is on PediaSure, but only takes about 15 ounces a day. We would like to hear from parents who have battled this problem and won. We need solutions, fast.

Our other question has to do with the "Milwaukee brace" she is supposed to wear for at least 12 hours a day. It is supposed to flatten her back and prevent any further problems from the scoliosis. However, it is extremely uncomfortable. While wearing it, Hannah cries constantly and is unable to do anything as simple as rolling over. The whole family becomes upset, and we finally just remove it. The longest she has kept it on is two and a half hours. She is normally such a happy baby that it's hard to see her so miserable. We would welcome any suggestions.

M.J. & D.J., Kentucky

Feeding System?

Our son was hurt in an accident three years ago. He can now move his arms and legs, but not in a coordinated way. We are searching for a feeding system that will allow him to feed himself.

He doesn't have enough forward head movement to use a mechanical feeding system, and he doesn't have enough shoulder movement to use a mobile arm support. Can anyone tell us about another type of feeding system or specific modifications they have been able to use?

M.W., Colorado

Leukoencephilitis

Our "normal" son was diagnosed with T-cell leukemia at the age of five and had a bone marrow transplant (BMT) one year later. Then he was diagnosed with leukoencephilitis, also known as Baló disease, a condition involving a loss of myelin in the brain. This condition apparently occurred as a result of toxicity to chemotherapy during the process of his BMT.

We were told that most children diagnosed with leukoencephilitis die shortly thereafter. My son is now 12 years old and has severe disabilities. He has seizures. He cannot walk or talk, and he has a feeding tube. I would love to talk with other parents of children with leukoencephilitis to find out how those children are doing.

E. L. & F.L., California

continued on page 16

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If you have difficulty entering and exiting your vehicle, the new Companion Seat® is your key to greater mobility. Its automatic operation and rugged construction enable semi-ambulatory persons to reliably and conveniently board Dodge Caravan or Plymouth Voyager minivans.

The seat extends 20" and tilts forward a full 6" to make boarding safe and easy. Once on the seat, you are smoothly raised into the vehicle by pressing the conveniently mounted switch. All you have left to do is manually rotate into the forward facing position. To exit, the procedure is simply reversed.

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If you need financial assistance, Chrysler offers cash rebates towards the purchase of adaptive equipment through the Chrysler Corporation Automobility Program. Ask your local Braun distributor about other sources of assistance.

For more information on the Companion Seat® or other Braun mobility products, call us today at 1-800-THE LIFT. We will give you the name and location of distributors in your area.

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Braun has recently released a helpful booklet entitled "Guidelines". If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All sources for motor vehicle funding are also listed in this Comprehensive booklet. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

BEST COPY AVAILABLE

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Caring For an Adult Sibling

My 54-year-old sister, Helen Marie, has mental retardation. She now lives with my mother in Chicago. After my mother dies, she will come to live with my husband and me in Atlanta. Helen Marie is sweet, kind and fairly self-sufficient. She takes pretty good care of herself and, in fact, is a big help to my 78-year-old mother. Helen Marie has worked in a sheltered workshop but would not be able to handle a "regular" job without many accommodations. She can be "stormy" if placed under any pressure, and she does need supervision.

Helen Marie has always lived at home, and I cannot see her adjusting to a more independent life. She knows she will come to live with us in Atlanta when my mother dies; in fact, she was part of the decision. She is very comfortable with us, and knows we both love her very much.

Here's the problem: My husband and I both work, and I do not want Helen Marie just hanging out in the house all day, watching TV and being lonely. Nor do I want her "taking care of the house." I want her to have a life, independent of my husband and me. I want her to be able to talk about what she did during the day and what she might do tomorrow. I am afraid if her life becomes a mirror of ours—as much as we love her—she will have lost something. I want her to know she is a separate person with her own thoughts.

My mother hasn't been well, and Helen Marie's world has become smaller since my dad and another sister died. Helen Marie is quieter now, and I feel like she is withdrawing. I don't want her world to become even smaller.

Helen Marie is used to frequent family gatherings and activities in Chicago. I've called different agencies here in Atlanta to see what is available for Helen Marie on a purely social level. None of the agencies can give me any answers while my sister is still in Chicago. As frustrating as that is, I understand. They are dealing with many people who need help now, and I'm looking for ideas for the future.

I hope to hear from someone else who has been in this situation. Can anyone give me hints on making my sister's transition as easy and positive as possible? Helen Marie will already be so sad about losing my mother, and I want so much for her to know that this is her home and we will be there for her—without smothering her separate and worthwhile personality in the process.

K.W., Georgia

Side Effects of Anticonvulsants?

My four-year-old son, Christopher, was diagnosed with a low grade astrocytoma brain tumor at eight months. He has undergone two surgeries and is on his second round of chemotherapy. He also had a stroke at eight months, which left him with left side weakness.

At 18 months, Christopher was walking and could say 10 words. At that time, he started having seizures. Initially, he was put on Phenobarbital. Then Tegretol was added. His doctors increased the dosages of both medications in an attempt to get the seizures under control. At that point, he began to stumble when he walked. Within a few months, he was unable to walk, talk or comprehend language. He also started to drool. I suspected that the medications were to blame, but the doctors told me this deterioration was not a side effect of the drugs.

He has been on the same combination of medications for three years now, and his condition has not improved. Has anyone else had similar experiences?

B.D., Colorado

EDITOR'S NOTE: David Hirsch, M.D., Editorial Advisory Board member and ASK THE DOCTOR columnist comments: "If Christopher's astrocytoma is no longer growing or expanding, and if he is not having any side effects from the chemotherapy, and if he has no other structural problems in the brain, such as fluid build-up, it is possible that the medications could be causing some—or in the worst case—all of his problems. Either one of the medications could be responsible, or the problems could be caused by the way this individual child reacts to this particular combination of drugs.

"If Christopher's seizures are stable, have his doctors tried eliminating one medication at a time? If one medication alone could control the seizures, I think it would be better to use only one drug. (There is a higher incidence of side effects with combinations of medications than with single-drug treatment.)

"I have seen these types of problems as side effects of anticonvulsants. They certainly are not unusual side effects of these medications, however, most children do not have problems as significant as Christopher's."

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond,
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Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT's 1995 Resource Guide* (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

1633

New Life Insurance Program

Easing the financial burden at a time of grief

by Frederic A. Moritz

It's a subject that is sometimes difficult to think about.

Who will take care of the financial burden in a time of grief after the death of a loved one with a disability?

Now there is one new answer.

Protective Life Insurance Company of Birmingham, Alabama has made available a simple, easy-to-apply-for term life insurance policy called Protective Provider. A toll-free call to 1-800-934-1929 will bring a free information packet on a specially designed term life insurance policy that can be used to cover funeral and burial expenses, or other expenses for children or adults with disabilities.

At a time of grief, Protective Provider can help with the healing. As children grow older, some parents can take comfort in the knowledge that their offspring with disabilities would be cared for in death, without imposing extra financial and emotional burdens on grieving survivors.

"There is a huge need for counseling the families of those with disabilities" says Protective Life's Vice President Mike Ballard. "As we talked to families, we found a need for this product," he explains. "We went to work to see how we could meet this need."

FINALLY, AFFORDABLE INSURANCE

In the past—given the insurance industry's reluctance to take on clients thought to be at higher risk—it wasn't easy for individuals with disabilities or their caregivers to buy life insurance.

In particular, it may have been difficult to buy more affordable "term life" insurance policies for individuals with disabilities, as opposed to the more expensive "whole life" policies, which also accumulate cash value.

"There has been some bitterness out there at the difficulty in getting life insurance for those with disabilities," says Rick Larson, who sells insurance for people with disabilities at the Cornerstone Financial Group in Burlington, Massachusetts.

THINKING ABOUT INSURANCE

Sometimes there is a reluctance to think about life insurance.

"Unfortunately, a lot of people haven't been prepared... this is one tool in planning for the future," says Dr. Gary Edwards, Executive Director of the United Cerebral Palsy Association of Greater Birmingham.

Dr. Edwards was one of those contacted by Protective Life during the planning phase for its new product, which has been available only for about a month now. In designing the new product, Protective Life planners consulted professionals working with people with disabilities, as well as families themselves, notes Mike Ballard, Vice President at Protective Life.

"It's not a glamorous product or a comfortable issue, but it's a serious issue," says Ballard. "Nobody likes to talk about dying. It's normally a painful and emotional subject... But, unfortunately, people die sooner than they expect."

Individuals who call 1-800-934-1929 will receive an informational folder on Protective Provider, with a clear, non-technical explanation of the policy and benefits, plus a straightforward application form.

"It's a good product," notes United Cerebral

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WHO WILL TAKE CARE OF THE FINANCIAL BURDEN IN A TIME OF GRIEF AFTER THE DEATH OF A LOVED ONE WITH A DISABILITY?

AT A TIME OF GRIEF, PROTECTIVE PROVIDER CAN HELP WITH THE HEALING.

The source of a parent's strength is in the love felt for their child. At Protective Life Insurance Company, the source of our strength is in the resources we have developed since 1907. We understand the importance of caring, planning and meeting needs. That's why we offer the PROTECTIVE PROVIDER℠, a term life insurance policy developed specifically for people with disabilities. For more information on the PROTECTIVE PROVIDER℠, call 800-987-6787. At Protective Life, we're someone to lean on at a time when you need it the most.

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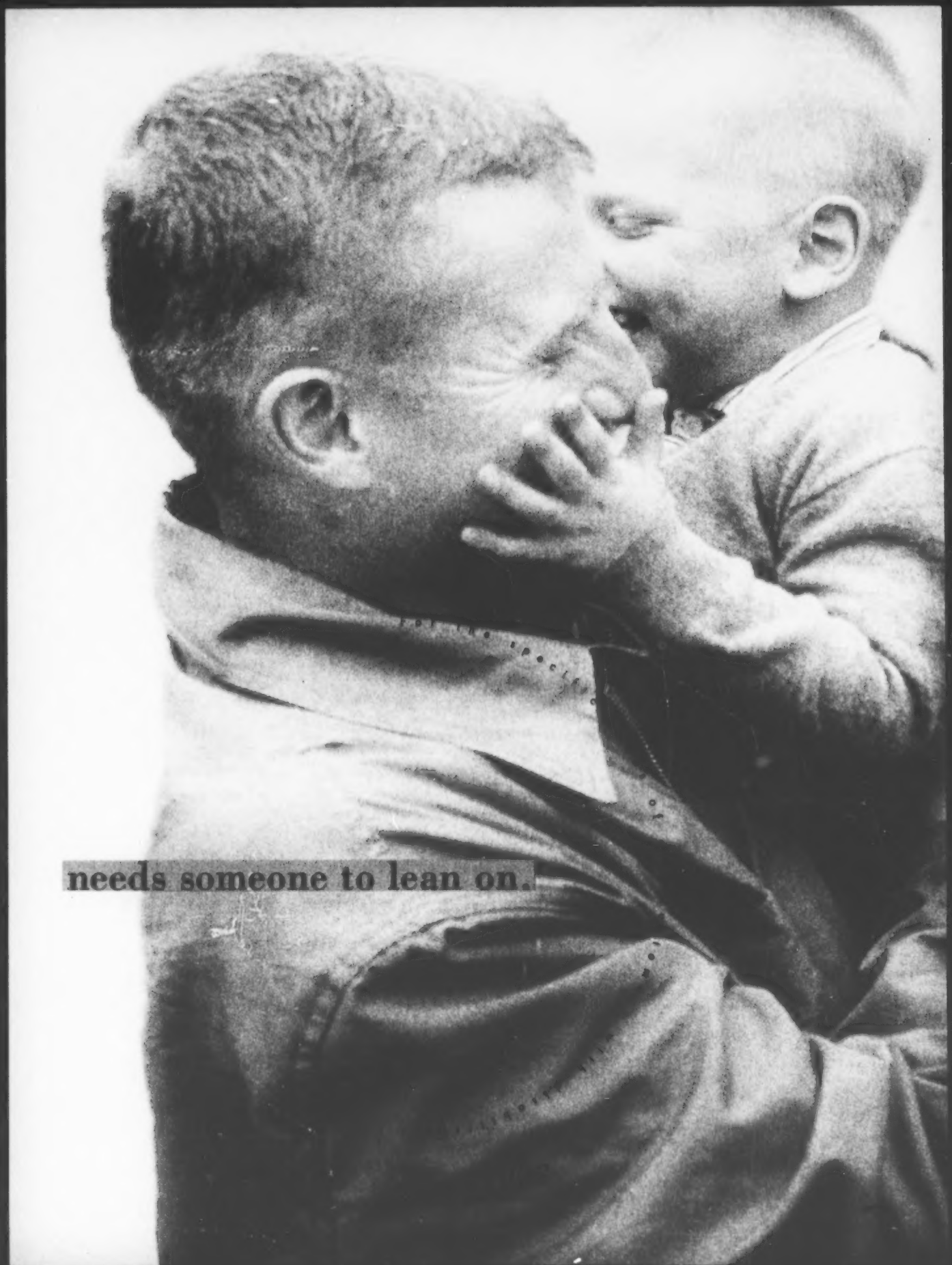
1035

Consult Policy Form TL-04 and U-573 for details, benefits and limitations. Not available in all states. If death occurs during the first two years a limited benefit will be payable. In most states this benefit will be equal to all premiums paid plus interest.

Circle #283


needs someone to lean on.

"NOBODY LIKES TO TALK ABOUT DYING. IT'S NORMALLY A PAINFUL AND EMOTIONAL SUBJECT..."

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Palsy's Edwards. "I am impressed with Protective's enthusiasm and willingness to do what needs to be done."

Protective Life has been promoting Protective Provider strongly in only a few states, but Ballard says nationwide marketing has now begun.

STANDARD PRICE

The Protective Provider provides a standard price for term life insurance in the amounts of $5,000; $7,500 or $10,000, regardless of the disability. Protective Provider's term life insurance can be issued between the ages of five and 55, and is available to age 70. Rates increase, depending on age attained, in five-year blocks. Premium payments may be made annually or semi-annually.

For example, in the age bracket five to 20, the annual premium would be $110 for a $5,000 policy; $130.50 for a $7,500 policy; and $140 for a $10,000 policy. At the age bracket 36 to 40, the annual premium would be $152 for a $5,000 policy; $161.25 for a $7,500 policy; and $171 for a $10,000 policy. In the age bracket 51 to 55, the annual premium would be $255 for a $5,000 policy; $344.25 for a $7,500 policy; and $425 for a $10,000 policy.

The policy does not require a medical examination, although the applicant must answer three medical questions attesting that the individual with a disability 1) is able to move about and eat, even if some assistance is required; 2) is able to function without the use of any artificial life support (e.g., ventilator, feeding tube, etc.); and 3) is free of heart disease, stroke, AIDS and all forms of internal cancer as diagnosed by a physician within the past five years. In the first two years of the policy, death benefits are limited to the return of premium plus interest (in most states). There is a two-year suicide and contestable period, and benefits are adjusted for misstatement of age. Without these limitations, Protective Life would have had to set the rates much higher.

A PRECEDENT FROM THE ARC

Protective Provider builds on the precedent for disability insurance set by The Arc, which offers its members the option to buy life insurance in the amounts of $2,500; $5,000 and $10,000. The Arc's decade-old program is geared mainly to those with mental retardation, explains Rick Fritsche, an Arc organization specialist in Arlington, Texas. "We were able to demonstrate to the underwriters that people with mental retardation are no more medically fragile than individuals without disabilities," he says.

By contrast, Protective Provider is targeted for a wider range of persons with disabilities. Customers who qualify pay the same price regardless of disability and regardless of differing mortality rates.

PART OF A WIDER PLANNING PROCESS

The Protective Provider death benefit policy is just one of a host of services provided by Protective Life. Protective Provider is available alone or as part of a family's larger planning process.

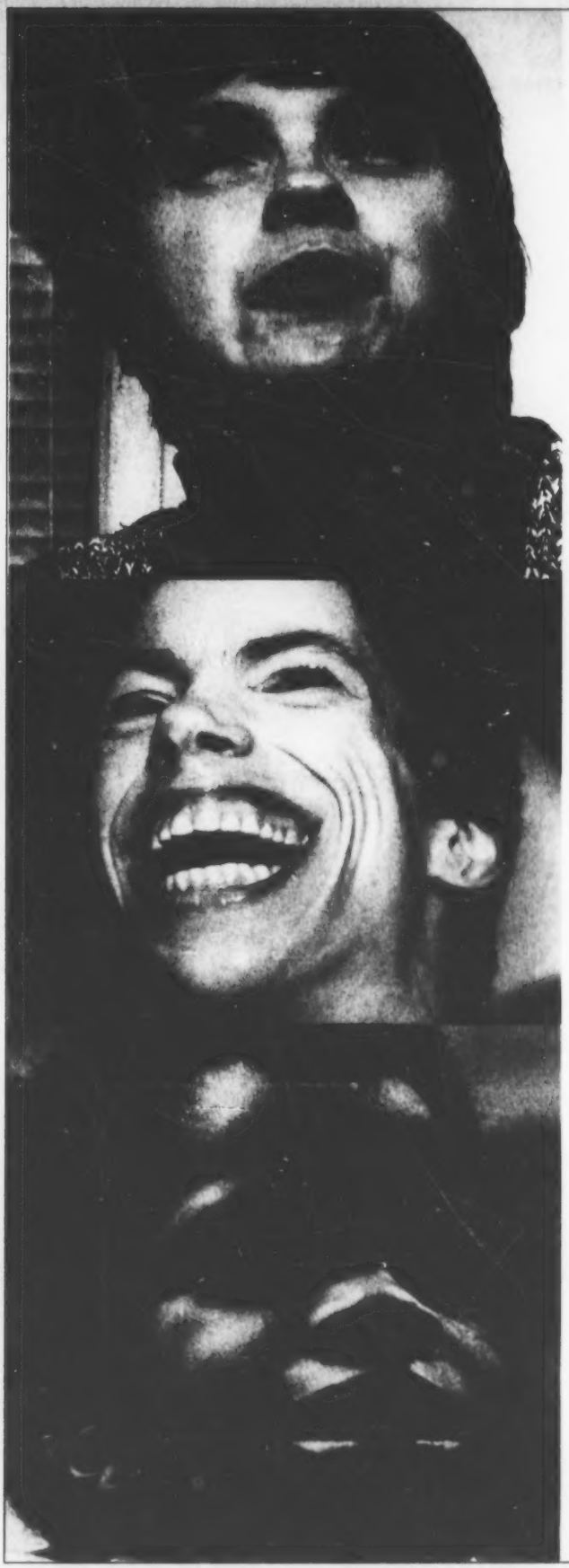
Estate Planning for Persons with Disabilities (EPPD), a Birmingham-based division of Protective Life, is available to work with caregivers and family members with disabilities to develop a comprehensive planning approach to provide for individuals with disabilities when caregivers can no longer function in that role.

In stage one, caregivers write a "letter of intent," summarizing the lifestyle and special needs of family members with disabilities. In stage two, a financial analysis is performed, geared toward determining what would be required to maintain that lifestyle in the event of caregivers' deaths. In stage three, legal requirements, such as a possible need for trusts, are analyzed. An attorney selected by the family can handle such needs. Stage four analyzes possible insurance needs that will permit a surviving family member with a disability to maintain his or her intended lifestyle.

Frederic A. Moritz was a journalist with the CHRISTIAN SCIENCE MONITOR for 13 years. He has also taught at Pennsylvania State University and Bucknell University. He is currently a graduate student at Boston College Graduate School of Social Work.

THE PROTECTIVE PROVIDER DEATH BENEFIT POLICY IS JUST ONE OF A HOST OF SERVICES PROVIDED BY PROTECTIVE LIFE.

1037



LOOK WHO'S SMILING NOW

Students at Oak Hill School are smiling because they...

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- feel a sense of pride and accomplishment in being a part of their communities.

And that's definitely something to smile about.

For more information about Oak Hill School's community-based education and residential program for children with severe multiple disabilities, contact the *Director of Oak Hill School, 120 Holcomb Street, Hartford, CT 06112, Tel: 860/242-2274, Ext. 851.*

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Circle #282

Supervising a "Runner"

L.K. (August 1995) has a three-year-old son, Jimmy, who has autism. Jimmy is considered a "runner;" if he is not constantly supervised, he will run away. L.K. has tried using a tracking device, but Jimmy refuses to keep it on. L.K. wanted to know how other parents of "runners" deal with this problem.

I had to write when I saw the letter about your "runner." There must have been other "runners" in history, but other than yours, mine and the "Wild Boy of Avignon," I've never heard of one.

My 10-year-old son, who has autism, has always been an escape artist. I don't know where he thinks he's going—just out! He wears a medallion necklace from Medic Alert that states his name, address and the fact that he is non-verbal and has autism.

We live in Minnesota so winter escapes aren't too common, but I usually call our hometown police in the spring to remind them that my son is around. When he gets away from home—usually about twice a year—he tends to go into people's houses. I worry because he's getting large enough that someone might mistake him for a burglar.

Otherwise, I have deadbolt locks on all the doors, and I keep the keys hidden. We have a security system that emits a beep when the door opens; that has foiled several escapes. I've removed all the window cranks and put duct tape over the little pins that hold the screens in place because he takes the screens out, opens the window and climbs out. Fortunately, his fine motor skills are not as good as his gross motor abilities, so he can't get duct tape off, untie knots or unhook chains. I also have locks on most of the interior doors so I can restrict him to certain areas within the house. This makes it easier to monitor him. Needless to say, I have to lock him in his room at night to keep him from escaping while I'm asleep.

He can never be alone outside. We have a fence, but now that he's bigger, it's easy for him to climb. He still has some tactile defensiveness and doesn't like to be in long grass and bushes, so I've planted a lot of bushes and vines along the fence to discourage climbing.

Making sure my other three children don't leave a gate open used to be a problem. No one could be bothered locking a padlock. Now I have a dog chain that clips the gate closed. My son can't get the clip undone and the others can get in and out easily.

Ours is a strange house to the uninitiated. They are welcomed at the front door and invited in; then the door is

For the first time a Special Auto Insurance *program* for Special People

ASK YOURSELF THESE QUESTIONS...

Q Are the modifications to your vehicle covered under your auto insurance?

Q If your vehicle broke down on the highway would your auto insurance cover the cost for special transportation to get home?

Q Does your auto insurance cover the higher cost to rent a modified replacement vehicle?

COVERAGE AVAILABILITY VARIES BY STATE

MOST PEOPLE DON'T HAVE TO ANSWER QUESTIONS LIKE THESE. THEY'VE NEVER NEEDED SPECIAL TRANSPORTATION FOR A CHILD WHO USES A WHEELCHAIR, OR PAID FOR A MODIFIED RENTAL VEHICLE, OR INSURED A CONVERTED VAN WITH SPECIAL EQUIPMENT.

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Circle 131

1939

closed and locked, and I run off to hide the key. We proceed on into the family room, as I lock the living room/dining room to make sure no one (guess who!) turns the table over or pushes the chairs down the stairs. Then I lock the kitchen door to make sure the microwave isn't pulled off the shelf and no one tries to wade in the fish tank. There! Now we sit down and visit!

Still, there are some advantages to having a runner. At school he has always had a one-to-one aide—and he always gets the youngest, strongest, fastest one.

Thinking his frequent escapes might be the expression of an unmet, deep-seated need for more exercise, I've tried to take him running with me. Guess what? He won't run even a quarter of a mile on a running path—it must all be in the chase!

This is the first year we've been brave enough to take him on vacation. Both times we've rented a large condo so he can have his own room that is secured for the night. I can do a lot with my trusty duct tape and some nylon cord. Then all I have to do is explain to the other kids why he gets the room with the two double beds and the three of them have to sleep in the tiny loft! Them's the breaks, guys!

I think the hardest part of parenting a "runner" is making some time for them to be a regular kid, to be a little bit free. You manage to come up with all kinds of strategies to keep them in and keep them safe. Finding a way to let them out, and let them take some risks is much harder. I don't have all the answers.

The park programs have provided my son with opportunities to try some things I could never help him with—snow skiing, water skiing, gymnastics, bowling. I'm always looking for activities that will keep him focused and engaged, so he won't be tempted to wander. The aides in these programs have been excellent. I just have to trust that they will be able to keep up with him, and he will come home at the end of the day.

A.H., Minnesota

It Isn't Fair!

K.S. and K.S. (September 1995) have a seven-year-old son with Down syndrome and a two-year-old son who has been diagnosed with neuroblastoma (cancer of the neural cells). They feel overwhelmed caring for two children, both of whom have problems, and wanted to hear from families who have dealt with similar situations. "This just seems so unfair to us," they wrote. "Everyday we ask how God could do this to us twice."

Ten years ago, I became pregnant with my first child. After years of infertility, I had come to accept that I would never have children. Nevertheless, I was thrilled to discover I was pregnant. Books were some of the first things I bought for the baby I was expecting. Intelligence was very important to me, and I planned to read to my child from the very beginning.

When the doctor told me my daughter had Down syndrome, I thought, "God, give me anything but mental retardation." I was knocked to my knees. Still, I decided that, no matter what, she would have a happy childhood.

Three years ago, I took her to see a movie. When we got home, my husband of 14 years was gone. He'd just taken all his things—no note, no goodbye. Our marriage was over. Once again, I was knocked to my knees. My daughter had lost her father, whom she loved dearly. Now, I could not even give her a happy childhood.

continued on page 24

Tell us about...

... parenting twins when one or both have disabilities.

Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

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Circle #166

RESPOND

continued from page 23

I made some terrible choices during that very difficult time in my life. I would have done anything to stop the pain I was feeling, even briefly. I became involved in an inappropriate relationship and ended up pregnant.

Although I cannot now imagine life without either of my children, I was devastated when I found out I was pregnant again. I did not want this baby. I could not marry the father and felt I could not offer the child a normal life. I was in desperate straits, both financially and emotionally. I was almost knocked to my knees again—but not quite. My legs were getting stronger.

Last May, my son, then 20 months old, was diagnosed with rhabdomyosarcoma, a highly malignant cancerous tumor of the muscle fibers. This time, maybe I swayed.

I am stronger now than I ever have been. At this point, it would take a hurricane to knock me over. Whenever I am faced with something frightening, I just remind myself about what I have already survived. Then I square my shoulders and go forward. I never chose to go through this pain, but I've stopped asking "Why me?"

It's not *me*. My daughter is the one with Down syndrome. I cannot begin to imagine her struggles. I do not know what it is like to be just smart enough to know you are not smart enough. I choose to have her included in a regular classroom because she has to learn to live in our world. But I have never struggled like she does.

My son is the one with cancer. He gets the chemo. He goes through the surgery, the discomfort, the pain and the sickness. He is the one with the life-threatening disease, not me.

Life is not guaranteed to include only a limited number of hardships. I've never believed I was a "special" person to whom God gave "special" children. There are no easy answers. The Bible says God knows when a sparrow falls, not that He keeps the sparrow from falling.

I wish you the best of luck with your struggles. May both of your children have long and fulfilling lives.

V.S., Arizona

1641

■ My husband and I have shared your feelings of "unfairness." We were most comforted by knowing that we were not singled out for rotten treatment. I sense that you need the same reassurance. Here, in a nutshell, is our story:

We have three daughters, now aged seven, four and two. Our first daughter, Elizabeth, was, and still is, an absolute delight—bright, funny, and beautiful. We so marveled at her that we couldn't wait to experience parenthood again.

Our second daughter, Kate, seemed perfectly healthy at birth. However, it soon became apparent that she wasn't developing as she should. When she was 11 months old, she was diagnosed as profoundly deaf. Just when we had gotten over that shock, we learned she had diffuse brain damage, probably as a result of contracting cytomegalovirus (CMV) in utero.

When Kate was two, our third daughter, Alexandra, was born. We had high hopes that Alex would be healthy, because Kate's problem was not genetic. I have to admit that I also felt somewhat "cheated" with Kate—a selfish feeling that has caused a great deal of guilt—and I looked forward to experiencing motherhood with Alex the way I did with Elizabeth.

Alex was born healthy. But at the age of nine weeks, she was diagnosed with neuroblastoma. A tumor on a nerve in her neck was removed, and she began undergoing chemotherapy. After our initial feelings of panic, my husband and I were struck by feelings of unfairness. We had always had faith in God, attended church weekly and treated people as well as we could. So why was this nightmare happening to us?

During my eight-day stay in the hospital with Alex, I embarked on a journey to find the answer to this question. I read the Bible and books written by people who had lived with tragedy. I talked with clergymen, family and friends. And I prayed. Looking back, I realize that this time was a catharsis for me, as well as the deepest religious experience of my life. One night in the hospital, as I held my baby, I had an overwhelming sense that *someone* was caring for my child. I'm not talking miracles or signs, just a sense that God loved my child.

I came to the conclusion that God didn't "do this" to Alex, that He was as sad about her sickness as we were. Somehow, to believe He was on our side helped me get over my feelings of betrayal. Moreover, Kate's problems, which had seemed so "tragic," suddenly seemed more manageable.

Alex has been off chemotherapy for two years now, and no one would ever know she had been sick. She's bright, beautiful and active. She has been a true blessing to the whole family. Kate is now in preschool. She is progressing, albeit slowly, and has become a joy to us.

Friends constantly ask how we have managed "so well." I'm sure you also hear comments like this: "I could never do as well with your situation. You are so brave." As you probably realize by now, that type of sentiment is bunk. You deal with things because you have to, not because you want to. But look around—in the papers, on TV and in the lives of your friends. Unfortunately, tragedy and hardship are not unique to you and your family. Have courage, keep your sense of humor and keep your faith. We will keep you in our prayers.

A.S.T., Arizona

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WORLDWIDE PATENTS PENDING

Circle #12

Alvin Law
Feet first!

Alvin Law, 35, is a motivational speaker who runs his own business, AJL Communications, with his wife, Darlene. In the past, he has worked in both television and radio broadcasting. He has also appeared on the television series "The X-Files," where he played the role of an "armless preacher." Alvin and Darlene live in Regina, Saskatchewan, Canada with Vance, Alvin's 10-year-old son from a previous marriage.

Alvin was born without arms after his mother was given the drug thalidomide during her pregnancy. Thalidomide, a drug prescribed for morning sickness in Europe and Canada in the late 1950s and early 1960s, was eventually found to cause an increase in births of children with limb anomalies. In 1962, thalidomide was taken off the market.

The following was adapted from an interview between Law and EXCEPTIONAL PARENT *intern Amanda Young.*

Alvin at 18 months—ready for a cold winter!

When I was born, the doctors told my parents I would require full-time care for the rest of my life. My parents decided they couldn't cope with that kind of responsibility. They were a farm family, and they made a decision about what was best for the farm. They left me in the hospital to be adopted.

The couple who adopted me were already grandparents. They decided to become foster parents because their two sons were no longer living with them. They were lonely and my mom, Hilda, was too old to have another child. My dad, Jack, worked long hours as a mechanic. Although they didn't have a lot of money, they sure had a lot of love. That sounds like a cliché, but they were just very special people.

Perhaps more importantly, they were practical people. They didn't shepherd me from hospital to hospital trying to find a "cure." They simply decided I was going to have to work things out myself.

I remember the first time my mother asked me to do the dishes. I looked at her and asked, "How?"

Her answer was simple: "Well, you're the one without arms—you figure it out."

Public school

My parents fought to have me attend the public school across the street from my house. It wasn't a political cause—they weren't trying to change the system. They were simply being practical. Why go across town to a special education school, when you could just go across the street?

I never recognized the magnitude of my going through the regular school system. School was school. However, I understood a little bit of the politics because I was in the principal's office the day he told my parents that I could attend. At that moment, I remember feeling I didn't belong. But at the same time, I was thrilled to go to the same school as my friends.

I was one of those kids who was often left out on the playground. I couldn't do all the rough stuff—tackle, fight, climb trees. My friends never deserted me, but they weren't going to push the other kids to let me play. So my sporting activities were based in my backyard. I played soccer, which was a natural for me, but it wasn't a big sport back then. I played hockey in the winter; I would just kick the puck. I spent each summer exploring, swimming and playing in the lake at our summer cabin. Those experiences became more important to me than sports.

Feet first

During my childhood, I went to rehabilitation hospitals every year from the time I was three until I was about 14. Doctors focused on training me to use artificial arms. Theoretically, these arms would work as well as real ones, but I became truly handicapped when I tried to use them. The prosthetic arms felt foreign—uncomfortable and heavy. They made me feel unlike myself. Because I had never *lost* my arms and hands, I had no instinct for using them. In the end, what I was born with worked best for me.

"During high school, music was the biggest part of my life," says Alvin. Using a special chair equipped with clamps to hold the instrument in place, 17-year-old Alvin used his feet to play trombone in the Yorkton City Band.

In fact, I was always pleased that I could do things with my feet that other kids did with their hands. I liked chemistry class because of the lab work. It was a point of pride that I never had an accident. My parents pushed me to be extra good at doing things with my feet. People notice it to this day. I'll be on an airplane and they'll hand out those little bags of peanuts. Most people will offer to open them for me. But I have no problem opening those bags. I work hard at trying to be dexterous. I'm a perfectionist; I make sure I don't have any accidents or little spills.

Joining the band

Looking back at my high school years, I realize that relationships with friends and girls were too important to me. I felt I needed many friends and a strong dating life to be

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accepted. The problem was that it never happened. I had good friends here and there, but our friendships became very complicated in high school.

The biggest part of my life during that time was the school band. When I was 11, I scored very highly on a music aptitude test at school. My mom got a phone call from the band director, saying, "We just can't let a musician like this slip by. We want him in the band."

My mom's immediate response was, "You don't know him, do you?"

Surprisingly, they invited me to join the band even after my mother explained that I had no arms. I learned how to play the trombone. The band director built a chair for me, with rods and clamps that held the trombone. I moved the slide with my right foot. In 1978, I actually ended up being rated one of the top ten high school jazz trombonists in the country. I played in an all-star band that year and won several competitions.

I didn't become a skilled musician overnight, however. I worked very hard at it. Music became my biggest outlet—the trombone, the drums on the side, and singing in choirs.

A new family: Alvin, Darlene and eight-year-old Vance Law. Alvin and Darlene were married in July 1992 in Yorkton, Saskatchewan.

On Saturday nights when other kids went out, I stayed home to practice. I didn't date, I didn't party, I had the trombone.

I blamed all of my social problems on my disability. Without question, high school was the most difficult period of my life.

Independence

After high school, I went to Mount Royal College in Calgary, Alberta, about 600 miles from where I grew up. I had decided to go into broadcasting, and Mount Royal was one of the two best broadcasting institutions in Canada.

I was not looking for education as much as independence. Mount Royal was perfect—it was a small college with about 4000 students. I made a commitment to myself that I was not going to worry so much about rejection, friends and everything that had seemed so important to me in high school. And it worked. Before I knew it, I was not only accepted by my peers, but I had started to date and go to parties. I became a bit of a social butterfly, like a lot of college students. But not at the expense of my marks—I graduated with honors.

continued on page 28

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Circle #107

Newlyweds Alvin and Darlene posed for the camera at every turn. Here they make the first cut into their wedding cake.

continued from page 27

Getting started

In 1980, I found a job as a radio disc jockey, and I worked in radio for almost a year. I didn't stay with it long because I was presented with an opportunity to become a lecturer during the International Year of Disabled Persons. A friend of mine had received a grant to do a year of programming for the schools. He couldn't take on the project by himself, so he asked me to help him.

I had learned communication skills in college, but I discovered my ability to lecture when I went on the road to speak to students. I'm always amazed when people say, "I could never get up in front of a group and talk." That's where I'm most comfortable!

Still, the hardest part about this kind of speaking is remaining honest with myself as I go out in front of audiences and open up my life. I was never an extremely private person, but I still felt reluctant talking about certain things. It was an eye-opener to me that I could do it, and I felt quite proud that people appreciated my doing it. I'd found my niche.

Positive thinking

Unless somebody can give me a better job than this one, which is unlikely, I'll probably be a motivational speaker forever. Before I found this career, I felt as if I was subject to society's whims; now I am in a position to bring about change.

I do approximately 250 programs a year in high schools all over North America, primarily in Canada. My speeches address self-image, self-esteem and positive thinking. They are designed like most motivational programs—meant to encourage positive thinking. I believe that if you have a positive attitude, good things will happen to you.

In my speeches, I stress the importance of holding on to the dreams and beliefs we had when we were young. Children are sure they can accomplish anything. When I was a little kid, I didn't doubt myself. That certainty came back to me later on, when I finally got my act together again. People call that kind of self-confidence "maturity." Is that maturity? I don't know. But now that I've been around the block a couple times, I can finally recognize what's important. **EP**

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Familiar Faces

Lauren Light, 12, of Chesterfield, Missouri and her brothers, Josh, 9, (left) and Aaron, 11, (right) enjoyed lighting the menorah candles during their family's 1992 Chanukah celebration. In addition to her love for holidays, Lauren also enjoys playing basketball, singing and dancing. Lauren's mom, Diane, describes her daughter as "beautiful, funny and very sociable." Lauren has a seizure disorder and mild mental retardation.

Last Christmas found four-month-old Vincent Ficarrotta posing amidst a plenitude of poinsettias! Mom Mary-Kay reports that Vincent loves to play with his Casio electronic piano, but his favorite "toy" is his four-year-old sister, Jeena. Vincent, who lives in West Babylon, New York, has multiple physical disabilities including arthrogryposis, a condition causing severely decreased joint mobility, and a variety of limb anomalies.

Is that a two-tone dog bone? Mom Penny caught two-year-old Kyler Aubrey sharing his Christmas candy cane with his "guardian angel," Molly. Kyler has developmental delays, but has not been diagnosed with a specific disability. His mother writes that Kyler is a happy child whose "smile is worth a thousand words." The Aubreys live in Statesboro, Georgia.

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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Circle #33

Members of the PACER Center Grandparent Program enjoyed a grandparent-grandchild picnic in June 1995.

Grandparents *Have Special Needs, Too*

by Jane Johnson

Clare and Ron Broos of Cottage Grove, Minnesota had raised five children of their own. They felt more than ready to become grandparents, and were thrilled when their first grandchild, Andy, arrived in August 1985.

Andy's physical development seemed fairly typical, but he cried a lot and never slept through the night. Still, Clare and Ron were anxious to have Andy spend a night at their house. How tough could one night be? But Andy would not go to sleep—none of Grandma's or Grandpa's tried and true methods worked. At 2 a.m., Clare and Ron raised the white flag; they called Andy's parents to come pick him up.

At Andy's two-year check-up, his doctor told the family that Andy had developmental delays "too severe to test." A few years later, he was classified as having pervasive developmental disorder (PDD), with impairments of social interaction, verbal and nonverbal communication and imaginative play.

Andy's grandparents were devastated. "We didn't know where to turn," Clare remembers. "We gave all the support we could to our children, but we had no one to turn to ourselves. We called around to see if any support was available. Someone referred us to the Grandparent Program at the PACER Center in Minneapolis. It was such a relief to find someone doing something for grandparents."

A unique position

Grandparents of children with disabilities often find themselves in a unique position. While expected to provide emotional and practical support to help their adult child adjust to the demands and stresses of having a child with a disability, grandparents may be struggling with their own uncertainty and grief. Lacking direct access to the information resources available to their children—doctors, social workers, therapists and other families of children with disabilities—grandparents may not receive sufficient information about the nature of a grandchild's disability or its effects. Many grandparents also feel an intensified level of sorrow; they grieve not only for themselves, but also for their adult child and their grandchild.

Many communities have services to meet the needs of children with disabilities and their parents, but very few ever consider the special needs of their grandparents. But grandparents have special needs, too. As Joyce Ratner, PACER Center volunteer and first co-chairperson of its Grandparent Program, puts it: "Being the grandparent of a child with special needs is the same as being the grandparent of any child, but it's different, too—right from the beginning. The birth of a child with disabilities introduces uncertainty and mixed emotions into an event that usually reassures grandparents that their family is continuing into the future."

Planning a network of support

In 1990, at the PACER (Parent Advocacy Coalition for Educational Rights) Center—the Parent Training and Information center (PTI) for parents of children with disabilities in Minnesota—advisory board member Sara Lieberman first raised the topic of grandparents during a discussion about ways to expand PACER's supports for parents. Lieberman, the parent of an adult son with a disability, recalled that her son's grandparents had also struggled with issues related to his disability. If PACER could help to meet some of the special needs of grandparents, Sara told the board, these grandparents could become a valuable source of strength and support to their adult children facing the day-to-day demands of raising a child with disabilities.

There were few program models to be found, so PACER Co-director Paula Goldberg decided to draw on the Center's experiences with parents. Time and again, PACER had seen that parents of children with disabilities became able to provide valuable support and practical advice to other parents once they became knowledgeable about disabilities and available services. Extended networks of support were a source of strength to parents; maybe the same model could work for grandparents.

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Pictures and stories

In 1991, PACER held two workshops to introduce its Grandparent Program. More than 150 people from throughout the state attended. The first workshop focused on ways to organize support groups for grandparents; the second dealt with issues of grief, loss and finding new dreams.

Following these workshops, a group of grandparents organized to become the Program's advisory board and planning committee. The planning committee surveyed grandparents to ensure that future activities would be responsive to their needs. Based on the information collected, they began to develop workshops, small support group meetings with educational and support components, and a grandparent-to-grandparent telephone network to provide support to new grandparents of a child with a disability.

The Grandparent Program philosophy asserts that grandparents are their own best resources. As one grandparent said, "I was overjoyed to walk into a roomful of people who understood how I felt without explanation. No one knows as well as someone who's been there."

The Grandparent Program support group meets throughout the year, led by grandparents who have been trained as group facilitators, with PACER staff members serving as information resources and consultants. Meetings have covered topics such as inter-generational communication, relationships between grandparents and their adult children, ideas for summer activities with grandchildren and much more. Many support group members have become advocates to maintain or improve the services their grandchildren receive. They offer encouragement, comfort, humor and advice to one another.

Above all, these grandparents enjoy doing what grandparents do best—proudly sharing pictures and stories of their grandchildren. A grandparent-grandchild picnic in June 1995 gave members a chance to match the real live grandchildren with the pictures and stories their proud grandparents had shared.

Members say the support group has reduced their sense of isolation. As one member told PACER, "This support group helped me get out of the closet. I now realize I'm not the only grandparent whose grandchild has a disability. I feel okay about asking for help to understand her needs and abilities."

Another member expressed how the group has enriched her relationship with her grandson, "The support group has relieved me of one of my biggest worries—that of concentrating solely on my grandchild's disability. Now, I see the child first, not the disability." **EP**

Jane Johnson is the coordinator of the PACER Center Grandparent Program. For a brochure or more information about the Grandparent Program, PACER's other projects or a free publication list, contact PACER Center, 4826 Chicago Ave. South, Minneapolis, MN 55417-1098; (612) 827-2966, V/TTY; (612) 827-3065, fax; e-mail: mnpacer@gteens.com.

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Circle #261

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Grandparents

"Normal" *A Grandmother's Point of View*

by Diane Bennett

The situation was out of my control. My daughter and her husband were not in any position to have a child, let alone a child with special needs! I wasn't ready to be a grandparent, and I definitely wasn't prepared to welcome a baby with missing genetic information. Why was this child determined to join us? If I had to have a grandchild, I wanted one with all the "normal stuff." I had raised my daughter with "normal stuff" in mind.

Images of normalcy surround us to the point that most of us take "being normal" for granted. Sure, once in awhile you see a child with "problems," but it's easy enough to glance away. Healthy, happy children make their way into our hearts on many of our favorite TV shows; baby magazines are full of how-to articles for parents of children who are growing and developing in typical ways; "normal" is implied in the advertising and packaging of each appealing baby product. This was the "normal" I knew. This was the "normal" I had expected. This was the "normal" I passionately wanted for my daughter—and, yes, for myself.

Diane Bennett holds her 14-month-old granddaughter, Mackenzie Lopez.

I DON'T KNOW IF MY LIFE IS "NORMAL," BUT I DISCOVERED THAT WHEN I WAS READY TO CHANGE, SUPPORT WAS AVAILABLE AND POSSIBILITIES SHOWED THEMSELVES IN A BRIGHT, NEW WAY.

Diagnosis

"Deletion," the doctor told us. "Mackenzie has a deletion on the end of the long arm of her twenty-second chromosome. She is genetically different from other children. You might say she is missing a small but important part. Her condition is quite rare. You will have to be patient and see how she progresses." He looked down at his notes and began nodding us toward the hall, then added, "It is difficult to determine the extent of her developmental delay. I'm sorry, but I don't have that much information to give you."

Mackenzie's diagnosis—and the little bit of information the doctor could provide—brought some relief, but it brought something else, too. I became increasingly sensitive to the frequency with which regular growth and development surrounded me, blasting me at every turn.

A simple trip to the grocery store threw me into emotional turmoil. By the time I hit the cereal aisle, I would have already wheeled my cart past scores of young, attractive parents with active, normal, adorable children.

It made me sick! I painfully resented their good fortune and health. Where was my wallet full of cute snapshots of my normal baby granddaughter? Why was my daughter beset by never-ending doctors' appointments, teary phone calls and an endless trail of paperwork?

Outside the boundaries

I had been carelessly tossed outside the boundaries of that safe world inhabited by my peers. I was living in a place where everyday events took on sinister shapes:

Just another shopping trip with a friend—my turn to drive so I swung by to pick her up. As she slid into the seat next to me, she excitedly said, "Look what Laura and Pam made in their Mommy-and-Me class."

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She was proudly wearing a pink tee-shirt with imprints of baby feet and the caption "I walk all over Grandma."

The rational part of me knew it was just a cute, silly tee-shirt, but the rest of me felt personally exposed and insulted. My heart jumped, my eyes welled and I quickly blinked back tears.

"How insensitive to flaunt that in my face!" I thought. "I'd love Mackenzie to walk all over Grandma! I'd love Macky to walk at all!"

Facing my fears

Months passed. I was constantly tired. I was always on the verge of tears, ominously aware of a vague cloud of fear that hovered in my mind. "Great," I told myself. "It was bad enough my daughter had a child with a disability. Now she's got a crazy mother, too."

Something had to change. The situation was not going to change, but I could. Other parents and grandparents had met similar challenges head-on. It was time for me to face my fears.

I began by volunteering in special needs classrooms and recreation programs. I fed children, took them out into the sun, turned on music tapes, wiped faces and diapered bottoms. I lifted kids into standers and positioned them on horseback. I listened to their assorted squeals and giggles. I saw a lot of grins.

I "hung out" at Macky's school, where my granddaughter and other infants rolled on the mats, played with the toys and received physical therapy. I rubbed elbows with courageous parents and skilled professionals.

Somewhere during this time, I heard the phrase, "Raise the child not the disability." I liked the tone of that. It jarred my perceptions. It felt like a place to start.

Cleaning out the "thought boxes"

Before Mackenzie' s birth, I could have told you exactly what I thought about almost anything. My rigid ideas fit nicely into sealed "thought boxes." I had empathy for the "special situations" of others, but when *I* came up against something that would not fit, something I did not want, something I could not change, it wreaked emotional havoc.

Mackenzie's arrival prompted some real cleaning of my "thought boxes." I had to learn to look for the whole rather than the parts, the similarities rather than the differences. I had to learn to see the child, not the disability.

Eighteen-month-old Mackenzie munches a cookie while showing off her newly-acquired skill of sitting independently.

Enjoying a day at the beach, Mackenzie, 17 months, "adjusts" Grandpa Bruce Bennett's swimming goggles.

In the process, I became the "normal" doting grandmother:

Both Mackenzie and I are all smiles and giggles as I hold her. She reaches out, first touching my nose, then my lips. Her hand brushes my cheek. One more stretch and she has the prize—Grandma's earring!

I've learned that "being different" coexists with "being normal." Love, joy, frustration, hope, anger, confusion, change, worry, playfulness, sorrow—these emotions are part of every parenting or grand-parenting experience. No matter what the situation, you do your best. You love. You wonder. You hope. You hold tight to courage. You develop faith.

I see my daughter doing these things and I am proud. I am moved by her love and early-found maturity. And I am captivated by my granddaughter, who is beautiful beyond words.

I don't know if my life is "normal," but I discovered that when I was ready to change, support was available and possibilities showed themselves in a bright, new way.

Mackenzie came into my world and changed everything. And I mean *everything.* Not just practical realities like care and money. Mackenzie has also given new meanings to more abstract realities—like what is " normal," what is fair, and what is possible. **EP**

Diane Bennett lives with Richard Cheek in San Clemente, California. Diane and Richard enjoy spending time with their extended family, which includes four adult children, a dog, a cat, a desert tortoise and two chickens. Diane recently returned to teaching at Westmont Elementary School in Huntington Beach, California after taking a two-year leave to be with her daughter, Molly, and granddaughter, Mackenzie.

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READERS TALK ABOUT:
Family

THE IMPORTANCE OF FAMILY

I was an only child, and accustomed to my privacy. Then I married Rich, the oldest of seven children. It took a lot of getting used to.

Rich's family was very close, and there were so many of them—five brothers, one sister, aunts, uncles, grandparents, great-grandparents, cousins, great-aunts and great-uncles. There were so many I couldn't keep them straight. When I was growing up, there were Mom, Dad, Grandma and me. We saw the rest of the family once in a while. But with my husband's family, it seemed like there was always some event happening, and everyone would be there. It was more than a little overwhelming.

When we started having our own children, my ideas began to change. Thanks to Rich's large family, someone was always available to babysit. And since Rich's youngest brother was just eight years old, he was always willing to play with the kids. A large family was starting to look like a better idea.

But it wasn't until our youngest child was born that both Rich and I realized the true value of a large, loving family.

Seven-year-old Ryan Carew had a front row seat at his aunt's wedding two years ago. With him were Poppy and Nana Jones and sister Amy, 10.

Ryan was born five weeks premature, and had a very difficult birth. After being transferred to a hospital specializing in infant care, he was diagnosed with hydrocephalus (fluid on the brain). Doctors told us he would be in the hospital for quite a while.

From day one, our families pitched in to help. Grandparents took care of our two older daughters, Maggie and Amy. The girls spent most of the next six weeks at my parents' house, and Rich's parents cared for them when my parents went to visit Ryan.

All of Ryan's grandparents came to visit as often as possible. These times were a great source of support. I will never forget the first time my mother held Ryan. He was hooked up to all kinds of tubes, but grandma could see nothing but her beautiful new grandson. I can still see her holding him as she sat in a rocking chair next to his bed. She rocked him and sang an Irish lullaby. I could feel the immediate bond that formed between them.

This past year has been an especially hard time for Ryan, and for the rest of the family as well. Ryan went from an active, vivacious seven-year-old to a child who could not get out of bed. He was having multiple seizures, and trouble with his shunt (the tube placed in his head to drain the extra fluid off his brain). Ryan spent two months in the hospital, and had five new shunts put in. As each one failed, he became increasingly weaker.

Our families rallied around us again, doing whatever they could to help. Relatives stayed with Ryan whenever Rich or I couldn't be there. They brought foods he liked to tempt him to eat and talked to him several times a day on the phone. Family members also took care of the girls, keeping their everyday lives as normal as possible. Those family members and friends who could not visit the hospital sent endless cards and letters. Ryan was thrilled by all the mail.

My perspective on extended family is much different than it once was. I now wonder how we would ever survive without them. They surrounded us constantly while Ryan was in the hospital, and far from feeling overwhelmed, I could only say, "Thank God they're here." Being part of a large family is great; I'm so glad our children are growing up with an intimate knowledge of how very important family is.

—Kathy Carew
West Haven, Connecticut

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT. In upcoming months, readers will be talking about:

- **Children's experiences at summer camp (March issue; deadline January 1)**
- **Family vacations (April issue; deadline February 1)**
- **Parenting twins when one or both have disabilities (May issue; deadline March 1)**
- **Twenty-five years of EXCEPTIONAL PARENT: For our anniversary issue, tell us what the magazine has meant to you (June issue; deadline April 1)**

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

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Love + Inclusion = Family

When our two girls were first diagnosed with Down syndrome (Melinda, 11) and cerebral palsy (Mary, 8), everyone in the family initially reacted with shock and denial. This was especially true at the time of Mary's diagnosis; nobody could believe that one family would be dealt two children with special needs.

I guess our feelings were pretty normal. But it didn't take long for us to feel the love of our relatives and friends. This love—so strong it felt like a warm embrace—is what helped us through those long first days. And soon the days were not so long. As the years have passed, our family and friends continue to share our moments of happiness as well as sorrow.

During an overnight visit to the home of Grandma and Grandpa Ennis, 11-year-old Mary spends some time working with Grandpa on his woodcarving hobby.

My husband's mother, Grandma Hettel, has always had a very special relationship with the girls. She is just old enough to be from a generation in which "different" children were kept out of sight. She is thrilled that this is no longer the case; she takes great pride in being a part of all the girls' activities and showing them off to her friends. Her arms are always open for big hugs from Melinda and Mary. Our family feels so lucky to have our wonderful Grandma Hettel.

Grandma Hettel celebrates a birthday with (from left) Mary, 4, and Melinda, 7.

My parents, Grandpa and Grandma Ennis, have always been my strength. Since I am their "little girl," I can still cry in their arms. Of course, they are also among the first to hear our joys as well.

My parents have a precious relationship with Mary and Melinda. No one tells a story like Grandpa Ennis. The girls love to cuddle in a big chair with him to hear "just one more." Grandma Ennis has a lot of energy. She can spend all day playing with the kids. My parents also love to have the girls spend the night at their house. They do this on an individual basis so these times are very special.

When it comes to our family and friends, the one constant—besides love—is inclusion. There is never a question about whether our girls will be welcome at any gathering. Our family is always well-received, made comfortable and included in all the action.

Our extended family and friends make us a fortunate family. To all of them, I humbly say, "Thank you!"

—Julie Hettel
Marseilles, Illinois

Papa and Nonie

Tommy's relationship with his Papa and Nonie, Norman and Jacquelin Janson, involves a bond that is difficult to put into words. I know, because I've already tried to write this several times.

Eleven-year-old Tommy, the second of our four children, has mental retardation. Because of his developmental delay, he still has some of the fears common to very young children. For example, the roaring dinosaurs at the Science Center terrify him. So when Papa and Nonie bring the other children to the Science Center, Tommy just can't go along.

One solution might be to leave Tommy out completely. Another would be to skip activities in which Tommy cannot participate, even if they are things the other children enjoy. Instead, Papa and Nonie decided that when the others do something Tommy doesn't enjoy, he should get his own special outing later, to MacDonald's or to the mall—two of his favorite places. At first this solution seemed too simple; Papa and Nonie thought they should do more. But they soon realized that the little trips were what Tommy wanted and enjoyed the most.

Of course, there are many places Papa and Nonie can bring all four children. And our other three children also have opportunities for individual time with Papa and Nonie. But Tommy and his grandparents are especially close.

Norman and Jacquelin Janson (aka "Papa" and "Nonie") celebrated their fortieth wedding anniversary with their grandchildren, (clockwise from left) Tommy, Stephen, Jimmy and Ellen.

I can see the love and trust on Tommy's face as I watch him sit by the window waiting for Papa and Nonie to come pick him up for one of these special outings. "Papa come pick me up," he repeats (about a million times) before they finally arrive. If he knows about a visit further in advance, he tells everyone he sees, even grocery store clerks. "Papa and Nonie coming Sunday," he

More Family continued on page 36

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delightedly announces to the world.

When we plan family gatherings, Tommy tells me, "Papa and Nonie come." They are always first on his guest list. When they arrive he runs out to greet them before they even get out of the car. Tommy is always ready to show them his latest video game. And Papa and Nonie are always ready to watch and listen.

Papa lent a hand with the games at Tommy's sixth birthday party.

Tommy knows that Papa and Nonie are two of the many people who love him. He loves them, too. Most importantly, he knows he can count on them. Seeing them together—Papa, Nonie and all four children—makes us very glad there's a Papa and a Nonie in our lives.

Susan Moore
Black Jack, Missouri

GRAMMY'S FAVORITE

When we were children, my two brothers, my sister and I always tried to figure out which of us was my mother's favorite. "We know you have a favorite," we'd tell her. "Who is it?"

My mother always insisted she loved us all equally. Now that we're grown and have our own families, we realize that's true. Mom really doesn't play favorites... Well, maybe with one exception—everyone knows she has a special place in her heart reserved for her six-year-old grandson, Bryant.

Grandmother Elaine Deane doesn't let a few tubes get in the way of a good snuggle with her newborn grandson, Bryant Paquette.

My sister and I got pregnant for the first time within months of each other. Lynn was a few months ahead of me and seemed to be having an easier pregnancy than me. Still, it was wonderful to share this experience. We enjoyed many ice cream sundaes and daily chats about what we had for breakfast—usually something fattening! I was with her when she gave birth to her daughter and looked forward to her being in the delivery room with me as well.

It was not to be. Bryant was born by emergency c-section—born with so many problems we could hardly keep track of them all.

My entire family, everyone from my 80-year-old grandmother to my cousins, rallied around to provide comfort and support. My sister visited the hospital faithfully, even though she lived more than an hour away and was caring for a newborn of her own.

My mother, however, was my most constant source of strength. Although my husband had to work every day, I never made that long drive to the hospital alone. During the four months Bryant spent in the neonatal unit, my mother accompanied me to the hospital daily, providing both emotional and physical support. She backed me up the day I sat in a meeting with medical professionals and fought to bring Bryant home. The doctors finally agreed, although they were not at all sure we could handle an infant who needed round-the-clock nursing care.

Bryant came home, on full life-support, to a miniature intensive care unit in our small apartment. During his first week home, he had a cardiac arrest—just the beginning of a traumatic first year we might not have survived without the support of my parents.

Bryant's surgeries have taken us throughout our home state of New Hampshire, and as far away as Pennsylvania and Tennessee. My mother has come with us every time. Along with her concern for Bryant, she always takes the time to make sure I'm doing okay. And it hasn't been easy. Now that I'm a mom, I can see how your children's heartbreak truly becomes your own.

Perhaps most important has been my mom's desire to really *know* Bryant. She has learned to care for his every need—from suctioning his tracheostomy to feeding him through his g-tube. But beyond his trach, wheelchair, leg braces and on-going facial reconstruction, my mother knows and loves Bryant for the unique little person he is. She is proud to be his grandmother and doesn't miss an opportunity to let everyone know it!

Grammy and Grampy Deane look on as 18-month-old Bryant plays with his "spare" CPAP (continuous positive airway pressure) valve. Bryant, who remained on full life support until the age of three, thought his CPAP valve was a great toy. To allow the real one to do its job, the family always kept a spare for him to play with.

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What can you say about that kind of unconditional love? My mother would argue that one just can't help love Bryant and, of course, I would agree. But the stark reality is that many people—grandparents included—just can't deal with a child who has a disability. We are extremely fortunate to have both of my parents, whose love for Bryant is manifested every day.

When other grandparents brag about the achievements of their "normal" grandchildren, my mother doesn't wait a minute to chime in with Bryant's latest accomplishments. Perhaps no one would really notice if she casually left Bryant out of these conversations. After all, she has three other "perfect" grandchildren. But to her, Bryant *is* perfect—and maybe even her favorite!

—Cheryl Paquette
Manchester, New Hampshire

Six-year-old Bryant listens to a story read by Great-Grammy Mary Labrie (left) and Grammy Elaine Deane (right).

BEST FRIENDS

Hoping for a "photo op," the local media turned out at the day camp for children with disabilities. As counselors helped children bait fishing hooks beside the lake, a reporter from the local television station asked if anyone was going to catch a fish.
"Sure thing," Bumpa told him. "Stay right here. Adam is going to catch one in no time!"
To everyone's surprise but Bumpa's, Adam caught his first fish within two minutes—just in time for a camera crew to film him for the local news that evening.

On summer vacation, Bumpa Bob Slagen and Adam Voisin, 3, do their morning stretches in a lawn chair in front of the cottage.

Adam is my three-year-old son, who has cerebral palsy, and "Bumpa" is my stepfather and Adam's best friend, Bob Slagen.

When Adam was born ten weeks early, we were told that his grade I brain bleed was not serious enough to cause any damage. The doctors said he'd catch up in no time. Eighteen months later, when he still couldn't sit unsupported, the doctors changed their prognosis and diagnosed him with cerebral palsy.

As is true for most working mothers, child care became a major concern for me. Adam and I had gone through three babysitters when Bumpa, who is retired, asked if he could take over.

I couldn't have asked for a better situation for my son! Bumpa and Adam always find something fun to do together. Sometimes they go to the local shopping mall just to ride the elevators, one of Adam's favorite activities. Bumpa and Adam ride all eight mall elevators, then come home. Bumpa has taught Adam how to fish, how to play his toy drums and how to draw a circle. He's also taught Adam the meaning of "coffee klatch"—of course, Adam drinks juice in lieu of coffee. I never have to be concerned about my underweight son consuming sufficient calories. Bumpa feeds Adam a full-course meal at noon. (Bumpa doesn't call it lunch; it's "dinner.")

Bumpa is so incredibly biased, it makes my heart melt. Every time, I start feeling bad about Adam's inability to walk, run or ride a bike, my stepfather is quick to pick me up. "That kid is the smartest three-year-old around," he asserts. And then he'll tell me about some other three-year-old he knows who isn't talking as well as Adam or can't even spell his own name. I sometimes wonder if Bumpa quizzes every three-year-old he sees!

I don't think I could ask for a better Bumpa to be at my son's side. These two "peas in a pod" are a fine example of what best friends are. The only thing separating them is 60-some years.

—Lisa Voisin
Muskego, Wisconsin

The next best thing to being there: Adam loves to talk to Bumpa on the phone. On this night, Adam called to tell Bumpa what Mom was making for dinner.

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Circle #284

"Project Cousins"

Discovering the joys of family

by Ann Darby

As the oldest of six children, my husband, Michael, was used to the noise and chaos of family gatherings. But I was an only child, and finding my place among my husband's close-knit family was an adventure and a challenge. Gradually, I came to love and enjoy the company of Michael's brothers and sisters, as well as the hectic life of a large family.

Spending a weekend at Grandmother's house are (from left) cousins Jaclyn, Lauren, Jason, Darby and Kevin.

Over the years, our extended family grew to include six spouses and 10 grandchildren; each new addition was welcomed with enthusiasm. The family shared our joy when we adopted our son, Kevin. And, although we lived miles apart, they shared our pain when Kevin was diagnosed with severe cerebral palsy.

Even though family gatherings had always been times of excitement and joy, part of me began to dread these get-togethers. These events had become times of "what ifs" and "if onlys" for me. As Michael's brothers and sisters shared the highlights of their children's lives, Kevin's accomplishments seemed to pale by comparison. One child had played a harp solo at church; another had been placed in the gifted program at his elementary school; a third was going to be in a dance recital. What was I supposed to say about Kevin? That he could now take a few steps without falling? That he had learned to pronounce a new word?

It was equally difficult to watch Kevin try to talk or play with his cousins. They weren't unkind; in fact, they were always very nice to Kevin, but they quickly tired of making the effort required to communicate with him and moved on to other activities. Kevin didn't seem to notice as much as I did. He just attached himself to that day's favorite uncle, seemingly content to spend his time with the adults.

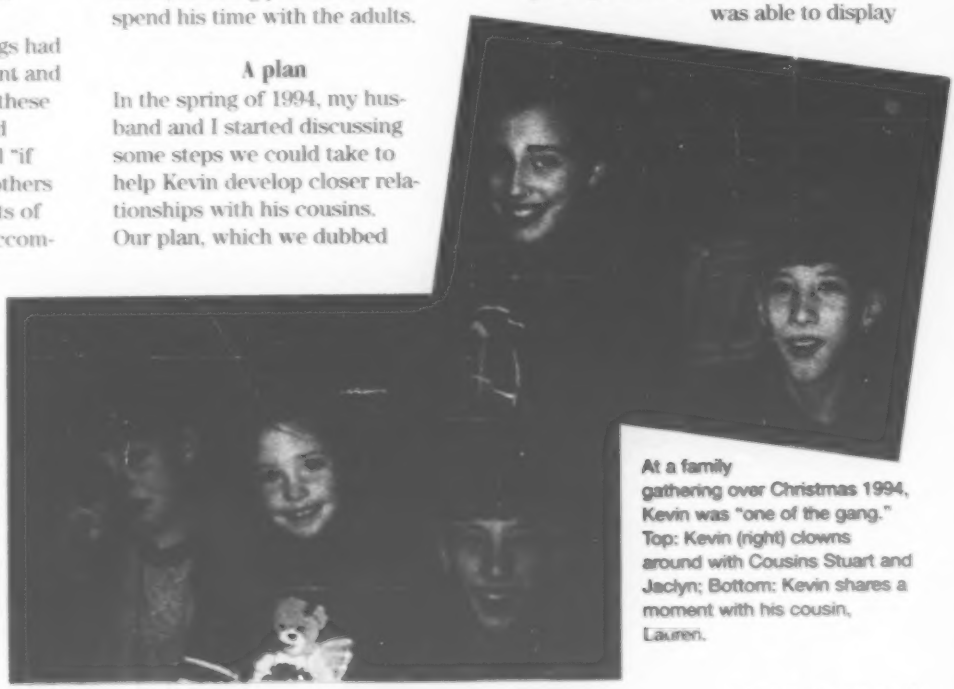
A plan

In the spring of 1994, my husband and I started discussing some steps we could take to help Kevin develop closer relationships with his cousins. Our plan, which we dubbed "Project Cousins," was the result of this brainstorming.

We decided to invite each cousin in Kevin's age group to visit us for several days during the coming summer vacation. We planned lots of fun activities for these visits—swimming, boating, fishing and riding Kevin's four-wheel, all-terrain vehicle.

In the comfort of his own home, we hoped our son would open up and talk to his cousins. Our goal was that Kevin and his cousins would discover how much they had in common.

That summer, five cousins spent "mini-vacations" at our home. We shared busy days full of summer fun—picnics, plays, movies and trips to the petting zoo. Just as we hoped, Kevin was able to display



At a family gathering over Christmas 1994, Kevin was "one of the gang." Top: Kevin (right) clowns around with Cousins Stuart and Jaclyn; Bottom: Kevin shares a moment with his cousin, Lauren.

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Even bath time is more fun when it's shared with a cousin! During a visit to Kevin's house, Stuart (left) and Kevin enjoy a soak in the suds before bedtime.

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his terrific sense of humor and love of life. Everyone seemed to have a great time, but we still didn't know if these "good times" would translate into greater family inclusion for our son.

Joyful holiday gatherings

The big family gatherings at Thanksgiving and Christmas would be the true test of our project's success. To our great joy, Kevin and his cousins seemed to pick up right where they'd left off a few months prior. No longer was Kevin hanging around the adults; he was off talking and playing with the other kids.

At one point, Kevin's grandmother complimented one of his aunts on the "kindness" of her son, who was playing a game with Kevin. Aunt Beth immediately corrected her mother; Stuart wasn't "being kind" and she hadn't asked him to play with Kevin—Stuart was doing what he wanted to do!

All five cousins have asked to come back to our home for visits. Several have already visited; other visits are in the works. The cousins have also included Kevin in trips to ball games and movies, a "cousins-only" party and a weekend at Grandmother's house.

Special gifts

In the end, the youngsters in our extended family were not the only beneficiaries of "Project Cousins." By making the time to have Kevin's cousins visit our home, Michael and I made five important discoveries of our own—Meghan, a talented musician growing into womanhood; Morghan, a kind-hearted and strong individual; Lauren, a creative writer and conversationalist; Darby, a nurturing and loving teacher; and Stuart, a bright sports enthusiast and our son's newest "best friend."

Kevin (left) and his cousin, Aaron, grab some potato chips during a "cousins-only" party.

In helping Kevin and his cousins get to know each other better, his father and I also got to know our nieces and nephews in a fresh, new way. We are thankful for the special gifts each one brings to our family. **EP**

Ann Darby lives in Beckley, West Virginia with her husband, Michael, and son, Kevin. Ann is a preschool teacher and Michael manages a Comfort Inn. Kevin, 14, attends Mt. Tabor Christian School in Beckley, where he is in seventh grade.

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Circle #14

1057

Getting Started

by Frank L. Brunetti

Estate planning always involves difficult decisions. The process is even more complicated for those families who must be concerned with the care, comfort and well-being of a child with disabilities, especially if it is clear that the child is unlikely to be able to provide for his or her own support or make mature day-to-day decisions. Such parents often worry about who will care for a son or daughter after their deaths; they also worry about ensuring that the child's needs will be provided for financially.

To begin the estate planning process, parents must focus on two tasks. The first is to perform an "inventory." The second is to retain an attorney with expertise in estate planning for children with disabilities.

The inventory

An "inventory" involves gathering and putting into order the most important documents that your fiduciary will need for the care of your child. (A "fiduciary" is the person you have selected as the personal representative of your estate, such as an executor, a trustee or both.) This inventory, which, for ease of reference can be kept in a three-ring binder, will include the following sections:

- **Part I: The Profile**—The profile should cover important information about the child's educational, therapeutic and medical history. It should include names, addresses and phone numbers for all the child's doctors, therapists and other service providers. It should also include key medical records, along with the names and dosages of all current medications. Finally, the profile should offer a complete description of the child's disability, and its likely effects on the child's life, both now and in the future.
- **Part II: Documents**—This section of the inventory should include the following: the child's' birth certificate (original or duplicate copy), the child's social security number, parents' social security numbers, name and address of the parents' estate planning attorney, name and address of the child's school or day care provider and a guardianship order and/or any other legal documents regarding the legal status of the child in the case that parents become unable to maintain responsibility for his or her care.
- **Part III: Living Plan**—A plan, written by the parents, describing how they expect the child to live out his or her life. The life plan should cover everything from the child's favorite activities and foods, to a list of friends and relatives—those with whom the child may live, others with whom the child should maintain contact. The plan should also include burial instructions for the child.

The preparation of the "living plan" need not be a "parent-only" task. In many cases, the child and other family members can participate in the process and may contribute useful information and ideas.

Finding an attorney

While parents are completing the inventory, they can take steps to find an attorney who has experience in estate planning for children with disabilities. Parent organizations or Parent Training and Information centers may be able to refer parents to a local attorney with expertise in this area. County bar associations may be another referral source.

It is important to retain an attorney with specialized knowledge because estate planning for a child with disabilities requires knowledge of federal tax law; regulations governing SSI, or "Supplemental Security Income," the federal program that pays a monthly stipend to people with disabilities, dependent on income but irregardless of age; state guardianship law and state Medicaid regulations. In addition, some states have enacted special legislation related to estate planning for children with disabilities. For example, certain states allow the establishment of "community trusts," nonprofit organizations that pool

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Estate Planning Resources

PUBLICATIONS

Planning for the Future—Providing a Meaningful Life for a Child with a Disability

By L. Mark Russell, Attorney, Arnold E. Grant, Suzanne M. Joseph, and Richard W. Fee. This book explains how to prepare a Living Plan, a Letter of Intent and a Special Needs Trust. It explains how to maximize your child's government benefits, avoid probate, reduce estate taxes and much more. Newly revised third edition, 1995, 440 pp. **$24.95.**

- *Available from EXCEPTIONAL PARENT Library: (800) 535-1910; Order #AP02400.*

The Life Planning Workbook

By L. Mark Russell and Arnold E. Grant. A hands-on guide to help parents prepare for the future security and happiness of their child with a disability after the parents' death. 1995, 272 pp. **$24.95.**

- *Available from EXCEPTIONAL PARENT Library: (800) 535-1910; Order #AP12700.*

A Family Handbook On Future Planning

This handbook helps parents understand and organize a future plan for a son or daughter with mental retardation. Includes information on wills, government benefits, support services, financial arrangements, guardianships, working with an attorney and other important areas. Forms, checklists and outlines, along with completed examples, help parents estimate their child's needs, and organize their estate to help meet those needs. 1991; 133 pp. **$15.**

- *Available from The Arc Publications; (817) 261-6003, voice; (817) 277-0533, TTY; Order #10-2.*

How to Provide for Their Future

By Elizabeth M. Boggs, Ph.D. and The Arc's Insurance Committee. This book provides suggestions for parents, guardians, attorneys and others concerned with meeting the lifetime financial needs of a child with mental retardation. Revised 1989; 46 pages; **$10.**

- *Available from The Arc Publications; (817) 261-6003, voice; (817) 277-0533, TTY; Order #10-1.*

NATIONAL PLAN ALLIANCE

The National PLAN (Plan Lifetime Assistance Network) Alliance is a service component of the National Alliance for the Mentally Ill. The members of the National PLAN Alliance are independent, not-for-profit PLAN programs that provide care planning services to parents who wish to continue the care they currently provide into the future when they are no longer able or available to provide such care to their adult children with disabilities. PLAN programs serve all disabilities.

All PLAN programs offer three key services: (1) developing a future care plan, (2) helping parents establish the necessary resources to fund the plan and (3) identifying the person(s) and/or program(s) responsible for carrying out the plan. Most PLAN programs also provide services to assist parents with current care needs. PLAN programs are currently operating in the following states:

ARIZONA
Arizona Proxy PLAN Foundation
2241 E Filmore St
Phoenix, AZ 85008, (602) 244-8166

CALIFORNIA
Proxy Parent Services Foundation
1336 Wilshire Blvd, 2nd Fl
Los Angeles, CA 90017, (213) 413-1130

CONNECTICUT
PLAN of Connecticut
PO Box 370312
W Hartford, CT 06137-0312, (203) 523-4951

GEORGIA
PLAN of Georgia
1256 Briarcliff Rd NE, Rm 421S
Atlanta, GA 30306, (404) 853-0494

KENTUCKY
Kentucky PLAN
102 E Main St, Ste 203
Georgetown, KY 40324, (502) 863-6609

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What will happen to your child with a disability after your death?

Easy to read and understand, an essential book, *Planning For The Future*, describes in careful detail the steps that parents should take—from residential, employment and social options to legal and financial elements—to ensure the future quality of life for their child. Highly acclaimed for its original introduction of the Letter of Intent!

What are people saying about this book?

"There are many complicated issues you face when you have a child with a disability. It is difficult to find good and accurate resources for many of the problems but when it comes to estate planning the place to turn to is books written by attorneys L. Mark Russell and Arnold Grant. They make even the most complex problem understandable and easier to solve. This is a "must have" book for parents and professionals dealing with estate planning for people with disabilities."

—Frank J. Murphy, Executive Director, National Down Syndrome Congress

"Expert information on this very important often complicated topic. Very valuable for parents and professionals."

—Stanley D. Klein, Ph.D., Editor in Chief, *Exceptional Parent Magazine*

"Planning is this book's overriding feature—no matter what the disability or how small or large the income, if there is a well-considered and thoughtful plan…children with disabilities will have a greater chance of enjoying the best possible health and security. This book is a must purchase for all parents who have children with emotional, physical, or mental disabilities."

—*Legal Information Alert*

"*Planning for the Future* is a book we distribute at all Arc events. We have found it to be a great deal of value and very easy to understand for all parents concerned about planning."

—Tony Paulauski, Executive Director, Arc of Illinois

"A comprehensive publication which presents an easy to follow approach to addressing vital questions and burning issues that caregivers and consumers encounter. A must for every professional in the field of mental retardation."

—B.R. Walker, Ph. D., Past President, American Association of Mental Retardation

"Using this book is probably the single most important planning step that you can take for your child."

—Professor Kenneth Friedman, from a review in *The Association for Persons with Severe Handicaps (TASH) Newsletter*

Newly available from the authors of *Planning For The Future*

While *Planning For The Future* discusses all the options in detail, *The Life Planning Workbook* is designed as a hands-on workbook to guide parents through the planning process. By completing the various parts of the workbook, parents can put what they learn in *Planning For The Future* to practical use. The workbook enables parents to: convey critical information about their child to future caregivers; calculate their child's lifetime financial needs; organize their affairs to permit continuity of care for their child after their death; save time and money by preparing in advance to meet with attorneys and other advisors. *The Life Planning Workbook* can be used separately or in conjunction with *Planning For The Future*.

To order your copy of *Planning For The Future* or *The Life Planning Workbook*–
Call 1-800-247-6553 (credit card orders only) or, send your check for $24.95 per book (be sure to include your address) plus $3.50 each for shipping to:

AMERICAN PUBLISHING COMPANY
P. O. BOX 988 • EVANSTON • ILLINOIS 60204-0988

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resources for the benefit of people with severe disabilities. In return for contributions to a community trust, a designated individual with severe disabilities can receive lifelong services such as administration of trust funds, advocacy (for example, participation by community trust representatives in the development of individualized plans developed by service providers) and/or guardianship.

Typically, most attorneys will give a free or reduced-rate initial interview. Parents should go to the initial interview with a specific goal—to determine whether this attorney can properly serve their needs, and for a reasonable fee. To be capable of making this determination, parents need to know something about relevant legal issues before going to the interview. These issues might include the Medicaid "resource" rule (the way their home state considers assets when determining eligibility for Medicaid coverage) and regulations for establishing legal guardianships in that particular state. This type of information is available through various publications and national organizations.

What are your concerns about estate planning?

Readers with concerns or questions about any aspect of estate planning involving a child with a disability may write to Estate Planning, c/o EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. Mr. Brunetti will answer reader questions in upcoming issues of the magazine.

Financial needs and liquidity

Before the estate planning process can begin in earnest, parents must determine the financial condition of their estate and decide if and to what extent their estate will provide for beneficiaries other than the child with a disability (for example, siblings). They will need to prepare an updated financial statement, as well as a family profile that outlines their particular estate planning needs. For example, if parents' assets include a family-owned business, they need to consider whether the business will be passed on to heirs or be sold. If the business is to be inherited by children in the family, the estate planner must find a way to pass the business on to the designated heirs without its assets being depleted by estate or inheritance taxes. If it is to be sold, sales arrangements should be made as part of the estate planning process.

Many families face the common estate planning problem of liquidity. "Liquidity" refers to cash or the ease with which other assets can be converted into cash. Because treasury bonds can be easily converted into cash, they would be considered "liquid assets." Real estate, on the other hand, would be considered "illiquid."

Liquidity is an important estate planning issue because parents need to determine whether their estate will have enough cash to pay for liabilities such as federal and local estate/inheritance taxes. In addition, if parents hope to set aside funds for the care of a child with disabilities, they need to think about where these funds will come from. Do they need to purchase life insurance, or should they transfer new or existing insurance coverage to an irrevocable intervivos trust (a trust established during the lifetime of its creator, which cannot be revoked)?

Writing a will

Once these preliminary steps have been completed, parents can begin drawing up a will. Because many forms of government assistance are denied to individuals with substantial assets, the will must exclude the child with a disability from inheriting or find an alternative way—such as a "special needs trust"—to maintain the child's eligibility for benefits and insulate the inheritance from government claims seeking reimbursement of previously paid benefits. [EDITOR'S NOTE: "Special Needs Trusts" will be the topic of an article in the February 1996 issue of EXCEPTIONAL PARENT.]

Another important feature of the will is the appointment of the executor (or executrix). The executor is the person charged with making sure the will's provisions are carried out. The executor must gather the assets, pay the liabilities, file tax returns and fund any trusts. Typically, the executor will be a family member or close friend. In some cases, particularly with complex estates, the executor may be a bank or trust company. An attorney or accountant usually assists the executor in handling the estate.

If the will provides for a trust, a trustee must be appointed to manage the trust until its termination. While the executor's term will be short-lived, the trustee may serve for years, even decades. Next to selecting a guardian, the choice of a trustee is the most difficult decision. The trustee must have

Estate Planning Resources

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MARYLAND
PLAN of Maryland & DC
912 Thayer Ave
Silver Spring, MD 20910, (301) 587-7815

NEW JERSEY
PLAN of New Jersey
1275 Bound Brook Rd, Ste 1
Middlesex, NJ 08846-1486
(908) 563-0300

NEW YORK
PLAN of New York
432 Park Ave S, Ste 1201
New York, NY 10016, (212) 545-7063

NORTH CAROLINA
Life Plan Trust
PO Box 20545
Raleigh, NC 27619, (919) 782-4632

OHIO
PLAN of Northeast Ohio
3130 Mayfield Rd, Ste GW 112
Cleveland, OH 44118, (216) 321-3611

PENNSYLVANIA
PLAN of Pennsylvania
110 W Lancaster Ave
Wayne, PA 19087, (610) 687-4036

RHODE ISLAND
SST of Rhode Island
PO Box 28411
Providence, RI 02908, (401) 464-3060

TEXAS
PLAN of North Texas
3300 W Mockingbird Ln, Ste 723, LB #2
Dallas, TX 75235, (214) 956-9933

VIRGINIA
Personal Support Network
100 N Washington Street, Ste 234
Falls Church, VA 22042, (703) 532-3303

WASHINGTON
PLAN of Washington
24226 9th Ave S
Des Moines, WA 98198, (206) 878-2562

This list of PLAN programs was obtained from the National PLAN Alliance. For more information, contact National PLAN Alliance, 195 Woodlawn Ave, Saratoga Springs, NY 12866; (518) 587-3372 (voice/fax).

NATIONAL INSTITUTE ON LIFE PLANNING FOR PERSONS WITH DISABILITIES
The National Institute on Life Planning for Persons with Disabilities (NILP) is a non-profit organization affiliated with Sonoma State University. NILP serves as a national clearinghouse for parents and professionals seeking the latest information about estate planning. NILP can provide information on a variety of topics including government benefits, legal issues, advocacy and guardianship and housing. It also provides a professional training program and designation—Chartered Lifetime Assistance Planner (ChLap)—for professionals who want to help families plan for their future. While NILP provides workshops on all aspects of life planning to parents and professionals, it does not provide any direct legal or financial services.
• Contact NILP, CIIS, Sonoma State University, 1801 E Cotati Ave, Rohnert Park, CA 94928-6922; (800) 854-3343; (707) 664-4235; (707) 762-2857, fax.

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several qualities: trustworthiness, sensitivity to the physical and emotional needs of the child with disabilities and ability to handle the financial affairs of the trust. A trustee must act almost as a surrogate for the parent. In some cases, two trustees may be needed—one to administer the financial aspects of the trust and another to carry out the more personal duties of the trustee such as personal visits with the child and advocacy on his or her behalf.

In addition, the parents must have properly drafted "powers of attorney," which grant another person the legal authority to carry out their affairs if they become unable to do so. In this event, it will be important that another individual is ready and willing to take on the role of "successor legal guardian," a role that gives this person legal responsibility to care for and act on behalf of the child with disabilities.

It's only human to put off making difficult decisions, but in most cases, parents of children with disabilities will have started the estate planning process without necessarily labeling it as such. Most parents will have information needed for an "inventory" readily available—though perhaps not yet organized in a three-ring binder. Many parents have already drafted a "living plan"—in their minds if not in writing. Some parents may have already discussed the issue with an attorney. All that remains is some basic organization and a decision to complete the estate plan within a specific time frame. **EP**

Frank L. Brunetti is an attorney and Professor of Law and Taxation at Fairleigh Dickinson University, in Teaneck, New Jersey, and maintains a tax practice in Hackensack, New Jersey. Mr. Brunetti has written for the ESTATE PLANNING JOURNAL *on the topic of estate planning for families who have children with disabilities. He also is an author and lecturer for specialized tax courses sponsored by the American Institute of Certified Public Accountants. He serves on the editorial advisory board of several tax publications.*

MEDIA

CEREBRAL PALSY: A COMPLETE GUIDE FOR CAREGIVING addresses the many complexities and uncertainties. At the same time, it provides the information parents, grandparents, caregivers and health professionals need—everything from medical, educational and psychosocial implications to wheelchair maintenance and dental care.

This book is available from Exceptional Parent Library (800/535-1910). The following is an excerpt from chapter two, "An Overview of Early Child Development."

How may the development of a child with cerebral palsy differ from typical development in the first year of life?

Developmental delays are anticipated for the child with cerebral palsy (CP)... The child with cerebral palsy most often does not accomplish gross motor tasks at the same rate as the child without CP, for example. Differences in the pattern of movement may be seen as well. Due to increased tone, or spasticity, some children with CP may not be able to fully separate the movement of their heads from the movement of the rest of their bodies, making their limbs feel and look stiff when they are rolling, attempting to sit or trying to walk. The child who is "floppy," or who has low tone, may not be able to generate the forces necessary to hold his head up or roll in a smooth pattern. This child may slump when seated or placed to sit, and may buckle or collapse at the knees when attempting to stand.

In terms of fine motor skills, small muscles in the hand that are used to manipulate objects are often affected by tone imbalances in children with cerebral palsy. In children with spasticity, or increased tone, impairment may begin at the shoulder, with the inability to extend the arm to reach for an object. The hand itself may be less controlled in fine regulation of movement, making it difficult for the child to reach and grasp. In children with an athetoid component, the "fine tuning" required to coordinate reaching, grasping and releasing may be missing.

The child with a known or emerging hemiplegic pattern may prefer to use one hand over the other... Hand preference usually doesn't emerge until about 18 months, so if your child does not use both hands equally when he or she is younger than 18 months, you should mention this to your child's doctor.

Language development and problem-solving abilities are not necessarily affected in the young child with cerebral palsy, although language delay and mental retardation do sometimes accompany cerebral palsy. You need to be aware of normal milestones and bring to the doctor's attention any behavior that is significantly behind what you perceive to be normal for a child of this age.

Many children with cerebral palsy are active and very social in the first years of life. A child with physical limitations, just like other children, seeks and needs verbal and physical affection in order for his personality and identity to develop. Visually impaired children, for example, often need more touching and verbal feedback than other children, since they can't rely on their sight to pick up a parent's soothing expressions.

You may find, however, that your child is less "huggable" and cannot return your embraces, but you shouldn't necessarily view this as your child's choice. A very small percentage of children with cerebral palsy exhibit autistic-like tendencies in the first year of life. These children appear to be in a "world of their own," neither seeking nor returning affection, eye contact or social contact. This behavior should be brought to the attention of the child's physician, and counseling may be initiated to help stimulate the parent-child interaction. **EP**

Excerpted from CEREBRAL PALSY: A COMPLETE GUIDE FOR CAREGIVING by Freeman Miller, M.D. and Steven J. Bachrach, M.D. (with Marilyn L. Boos, R.N.; Linda Duffy, P.A.-C.; Douglas T. Pearson, Ph.D.; Rhonda S. Walter, M.D. and Joan Lenett Whinston). Published by The Johns Hopkins University Press, 1995.

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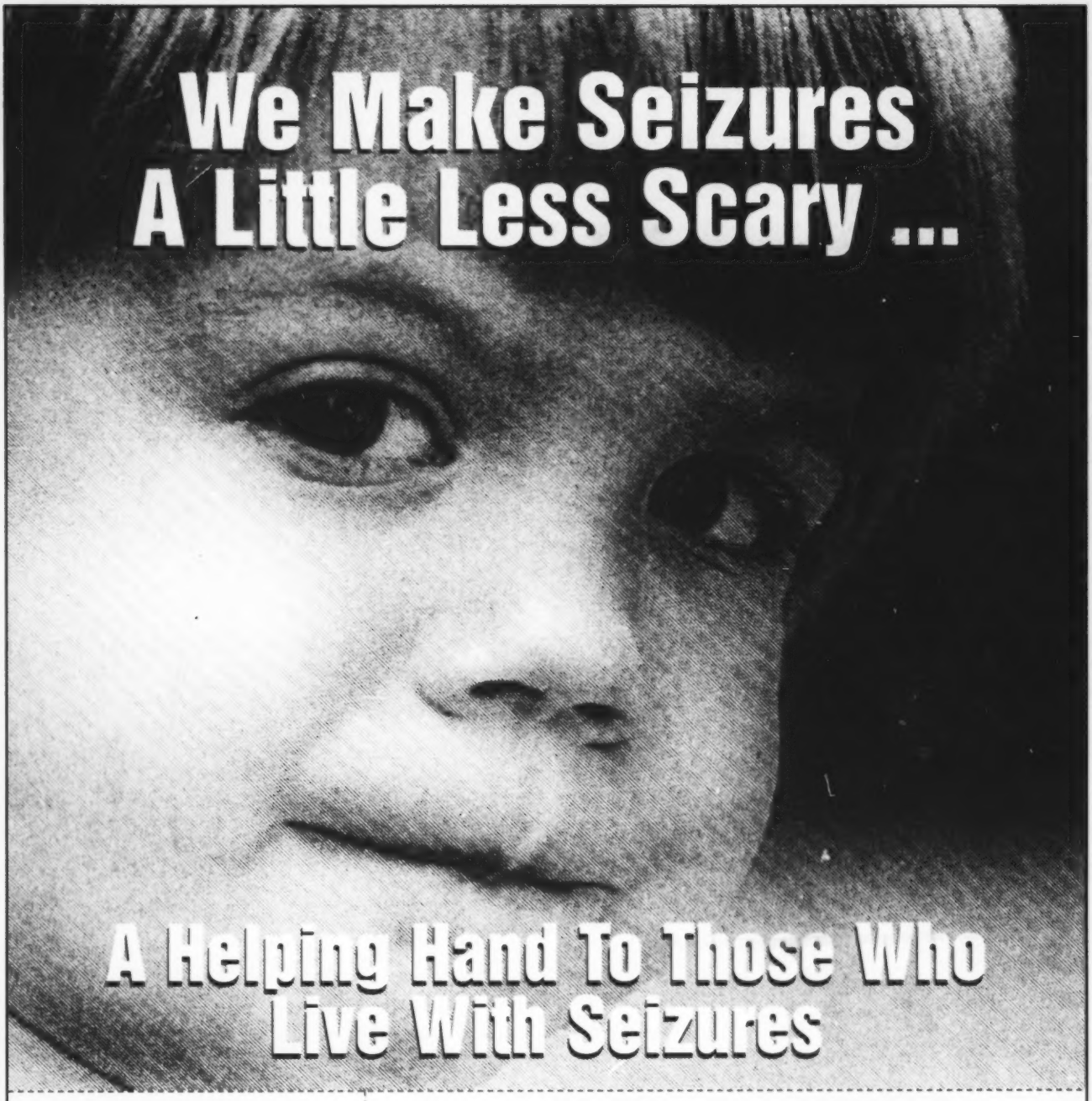

Epilepsy Foundation
of America.

4351 Garden City Drive
Suite 500
Landover, MD 20785

(301) 459-3700 or
(301) 577-9056 (FAX)

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City _____ State _____ ZIP _____

The Reauthorization of the IDEA

by Sen. Bill Frist

It gives me great pleasure to give you a status report on the reauthorization of the Individuals with Disabilities Education Act (IDEA). The Senate Subcommittee on Disability Policy has held three great hearings on the IDEA where we have established a clear and compelling record of what the IDEA means to children with disabilities and their families. In July, we tackled the tough issue of discipline, holding a balanced hearing on what might be done to protect the rights of children with disabilities, while recognizing the responsibility of school personnel to maintain safe schools. Through the appropriations process, we are working to secure vital IDEA funding, especially for the state grant programs ande Parent Training and Information centers.

We will have a draft of the reauthorization bill for the IDEA ready for public comment on November 20. (To obtain a copy of the draft, contact the Senate Subcommittee on Disability Policy, 422 Dirksen Senate Office Building, Washington, DC 20510.) This legislation, when signed by the President, will be the blueprint that will guide educators' actions as they work with the special young people we care so about. This blueprint will open up new opportunities to children with disabilities. The effects of what we do will be felt into the next century.

We have spent many months reading and talking to people about how to best serve children with disabilities through the IDEA. As Chairman of the Senate Subcommittee on Disabilities, I laid out five major principles to shape the legislation:

- First, children with disabilities and their families should be the central focus of our drafting efforts.
- Second, if a current provision in IDEA works, don't undo it.
- Third, add incentives that encourage schools to serve children based on needs, not disability labels.
- Fourth, add incentives that encourage and prepare schools to include children with disabilities in school-wide innovation, reform efforts, and assessments of student progress.
- Finally, clearly link discretionary programs (federally-funded competitive grants for projects or research aimed at improving services for children with disabilities, conducted by universities, state boards of education or other agencies) to the state grant programs (federal funds provided to help states cover the excess cost of special education). With this link in place, discretionary grants will help educators educate children with disabilities and help families contribute in meaningful ways to the education of their children.

Specific examples

I want to give some specific examples of what we have done in our draft, examples that are consistent with my five principles:

In our draft, we have removed ambiguities with regard to parent participation in placement decisions affecting their child. Parents will participate, period.

In our draft, we have not changed the state grant funding formula. We have not removed the categories of disabilities that define a child's eligibility. I am in no mood to experiment with funding formulas or new definitions of what constitutes a disability. Such actions may have unintended consequences for children with disabilities and their families.

In our draft, we allow educational agencies to use IDEA state grant funds to coordinate services with other agencies to benefit children with disabilities and their families. We allow children without disabilities—when served along with children with disabilities—to receive the incidental benefit of state grant programs. I want school personnel to be empowered to help children without thinking about eligibility status. I want school personnel to be empowered to minimize the effects of and prevent disabilities without worry about a child's eligibility status.

In our draft, we give local educational agencies the option of implementing school-based improvement plans designed to benefit children with disabilities and their parents. I anticipate that this provision will help school systems to focus more on the prevention of school failure, to use school personnel in flexible ways and to increase the opportunities for children with disabilities to be part of special projects and initiatives. If school districts opt for this flexible use of some IDEA dollars, it would not in any way lessen their obligations to comply with the IDEA with regard to any child with a disability.

Let me give one more example. In our draft, using multiple strategies, we make the discretionary grant programs catalysts and support systems for educational agencies and personnel who work with children. We require personnel grants, which fund personnel preparation and training, to better address staff shortages identified by states. We require that researchers make research results available to teachers more quickly. We give states the opportunity to compete for grant funds to tackle systems-change problems, such as how to include children with disabilities in state- and district-wide assessment of student progress.

In our draft, we retain the authorization and separate line item for the Parent Information and Training Program so these centers can continue their important work.

Discipline

Now for the $64,000 question. We are working toward a bipartisan, multiple group consensus on provisions with regard to discipline. We are very close. Everyone has invested much time and thoughtfulness in bringing us to where we are today. This work will pay off. The discipline issue will not undermine a child's right to a free, appropriate, public education. I hope you will join us in the final steps to true consensus.*

Wonder, confidence, love and trust

As I think back over the last eight months, certain moments stand out for me. I remember making a few remarks at the NPND reception on a cold March evening. As I was about to conclude my comments, a little person with big, bright, beautiful eyes crawled across the floor to my feet. As I picked up that special little child, I saw many things in those eyes—wonder, confidence, love and trust. At that moment, I knew and understood why I accepted the chairmanship of the Senate Subcommittee on Disability Policy. My job, with your help, is to ensure that all children with disabilities experience wonder, develop confidence, and are loved by and can trust the people around them at home, in school, and throughout their special lives. **EP**

On November 8, 1994, Senator Bill Frist (R-Tennessee) became the first practicing physician elected to the U.S. Senate since 1928. Frist is a member of the Senate Budget, Labor and Human Resources, Commerce and Small Business Committees. He is Chairman of the Senate Subcommittee on Disability Policy. This article was adapted from remarks made by Senator Frist at the NPND Annual Meeting on October 2, 1995.

* For more information on how the IDEA reauthorization process may affect disciplinary procedures for students with disabilities, see "IDEA Reauthorization Update" (NETWORKING, October 1995) and "'Special Ed' Deserves Special Emphasis" by Rep. Randy "Duke" Cunningham (November 1995).

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Questions and Answers About Managed Care

by Family Voices

Once, the words "health reform" were on everyone's lips. Now we hear about "managed care." What is managed care? Is it health reform? Is it good or bad for children with special health care needs? Although "managed care" means different things to different people, this article will try to explain what most people mean by the term.

What is managed care?

Managed care is a way of providing pre-paid health care within a network that includes a specified group of health care providers and services. The network coordinates and refers patients to its health providers and hospitals, and monitors the amount, patterns, cost and quality of care delivered.

Managed care differs from traditional "fee-for-service" plans, in which patients choose their doctors and other related services and pay for each service. Managed care plans usually limit the services patients may receive by making physician visits, therapies, home-care, pharmacies, specialists, clinics and hospitals available within their own system, and by using "gatekeepers" to prevent the provision of "unnecessary" services or excessive referrals outside the network. Managed care is not "health reform;" it is a way to finance and deliver health care.

How does it work?

Managed care plans are corporations —either for-profit or not-for-profit—serving large groups of people through a "capitated" system. This means that a business, school system, government body or membership organization pays the plan a set price for each employee's or member's health care coverage. The employer and employee usually share premium costs, and there might be a small charge (or "copayment") for each service. The physicians and providers in the network are on salary; they are not paid a fee for each service provided. Someone—often a primary care physician or nurse—is the "gatekeeper," deciding which services will be provided and whether referrals outside the network can be made. Keep in mind that "case management," in which an individual coordinates services for patients, is *not* the same thing as managed care, although case management can be part of managed care.

What are some examples of managed care?

- **Health Maintenance Organizations (HMOs)** are the most common form of managed care; all health services are delivered and paid for through one organization, often in a single location.
- **Preferred Provider Plans (PPOs)** offer a group of doctors and hospitals who give a discount on their services to an insurance company or an employer. In a PPO, consumers must choose their primary health provider from an approved list and must pay extra for specialty services received outside the PPO group.
- **Medicaid managed care plans,** adopted by many states, restrict Medicaid patients to a specified network of health care providers and services. States must obtain a waiver, known as an "1115 Waiver," to implement this kind of plan. (A waiver represents a situation in which a specific state applies for, and is granted, exemptions from standard Medicaid rules.)

Why is managed care considered so effective?

As health care costs have risen over the years, policymakers and health economists have seen managed care as a way to save money. They believe that managed care plans—where everything and everyone is part of a controlled network—can achieve cost containment. Many health professionals also believe that a managed care system can provide care coordination and quality control.

What happens to children with special needs under managed care plans?

Because many managed care plans are new, data about their effects on our children are scarce. However, there seem to be good and bad points. Possible advantages include the following:

- Care coordination is easier.
- There are fewer out-of-pocket expenses.
- Health care needs are often taken care of in one place.
- Unnecessary procedures are unlikely to occur.
- Providers and services are closer to home.
- Consumer satisfaction is often a priority.
- Continuity of care is likely.

Disadvantages, however, also exist:

- There is a cost disincentive for making referrals to out-of-network specialists for rare disorders or pediatric specialty care.
- "Gatekeepers" may lack knowledge and experience about some disabilities or specific conditions.
- It may be difficult to obtain access to specialty equipment, therapies, new medications or treatments.
- Access to pediatric specialists may belimited.
- It may be difficult to get objective second opinions.
- In many managed care situations, it is unclear how patients and policymakers monitor the delivery of care, participate in patient and network decision-making and lodge complaints.

In general, it is important to remember that the expense of providing timely, appropriate and quality care to children with special health care needs may create a dilemma in a system that is based on cost-containment.

What should you do if managed care is offered?

Ask many questions: Who are the "gatekeepers" and what are their qualifications? Who are the pediatric specialists? Can you choose your own primary physician, pediatrician, specialist and therapist? Does the plan include the therapies, access to specialists and unusual treatments or medication your child requires? What will it cost to go to a specialist or provider outside the plan? Who gives and pays for second opinions? Is there a program or department for children with special health needs? Is there a consumer board, and what are its responsibilities and powers? How are doctor-patient decisions made? What are the grievance procedures? What state or federal body monitors the managed care plan, and are reports available?

Families should insist on the involvement of consumers in the network's policymaking, quality assurance and grievance procedures. **EP**

Family Voices is a national, grassroots clearinghouse for information concerning health care for children with special health needs. Family Voices monitors public and private sector health care changes affecting children and families through the collective efforts of member families, a volunteer coordinator in every state, 10 regional coordinators and a small staff working in several locations around the country. For more information, or to share your concerns about managed care, contact Family Voices, P.O. Box 769, Algodones, NM 87001; (505) 867-2368; (505) 867-6517 (fax).

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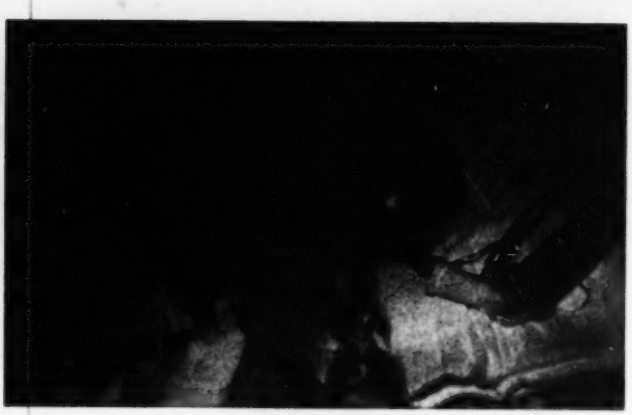

Reese Elliott, at one week old, had dropped to one pound, 11 ounces. Here, his father holds his hand.

Surviving

by James Elliott

Parenting children with disabilities can be brutally difficult. Each of us must deal with this fact on a daily basis, though most of us find it hard to confront. How many times do you hear or read about this side of our lives? The harsh realities that find us privately raging against everything? The media usually offers inspiring, hope-filled stories about sick kids and their brave, loving parents. These stories don't paint a complete picture. Would reading any of these stories prepare the new parents of a child with severe disabilities for what lies ahead?

The lives we live as parents of these kids are routinely portrayed as a-okay, as long as we show a "positive attitude." The truth gets lost in people's need to maintain a strong, socially acceptable, outward appearance. This need brings people too close to the edge of total denial.

Reese, James and Marchelle Elliott spent their first Christmas together in the NICU at the St. Joseph Medical Center in Burbank, California.

In all honesty, it has been my experience that raising a child with severe disabilities is generally not enjoyable. This is not to say that good times never occur, but the times of true happiness are so few when compared to the times of sadness, pain, guilt, pity or all-out exhaustion. I am upset when people imply that I'm simply whining about my life. My feelings do *not* grow out of self-pity or selfish regret; I have no room left in my heart for such things. My sadness and pain come from the anguish of watching my child suffer more often than not.

I love my son intensely, and I'm thankful that he is alive. But I refuse to pretend I'm at peace. I wouldn't wish my family's life on my worst enemy.

I've learned a lot from our experience, but I compare my feelings to those of a returning combat hero, standing under bright lights during some medal ceremony. The soldier stands there blinking, trying to accept accolades from the crowd, when inside all he knows is that he had to watch his buddy get his guts blown out on the battlefield. He knows he just happened to be the guy left alive to try to save his friend. This is not a peaceful knowledge. He knows he survived, that's all. There can be no peace with the rest, and no denial of the nightmare he had to live through—not until someone finds a way to set back time, to prevent that shell from exploding, to relieve him of the painful memories of a loved one's suffering.

My son, Reese, was born three months premature, after my wife went into spontaneous early labor for reasons doctors could never explain. She was in perfect health, did everything right, and Reese still came early. He was yanked from the womb weighing just two pounds, in an emergency c-section, and rushed to the NICU. There, he was hooked up to I.V. tubes, sensors and monitors.

The doctors told us to find the hospital chaplain. Before my son was a day old, I watched a priest give him his last rites. All I could ask was a simple question—what kind of God would allow this child to be born, just to suffer terribly for a day or less and then die? What possible good could come of this situation? I started to feel a deep anger, which, even now, I grapple with daily.

Reese surprised everyone and hung on through four grueling months of brain hemorrhages, spinal taps, transfusions, countless I.V. punctures, seizures, brain surgeries, eye surgeries, abdominal surgeries and more.

The end result of his suffering was severe. Reese will live with permanent blindness, cerebral palsy from the brain damage, an inability to swallow most foods (he is fed through a tube in his stomach), hydrocephaly (an inability of the brain to drain its own fluids—a plastic shunt in his head keeps him alive), microcephaly (stunted head and brain growth), a seizure disorder requiring permanent medication, extremely limited physical ability (he can't roll over, crawl or walk) and a host of other medical problems.

I would step off a cliff with a smile on my face to prevent my son from suffering anymore. But the simple fact

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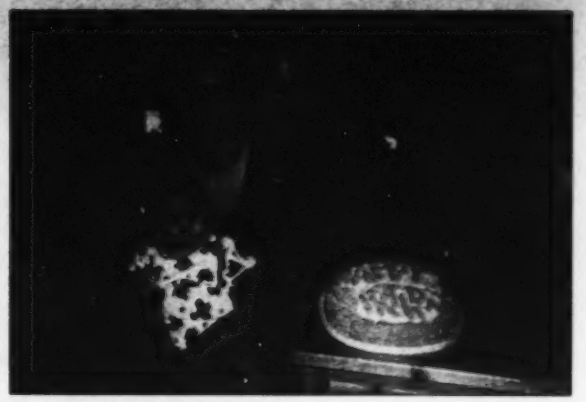

James and Marchelle celebrated Reese's first birthday with him.

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is that I am in for a lifetime of watching my brave little boy suffer in ways that will break my heart over and over again. This is true for most of you also.

Surviving this life is what makes an exceptional parent truly exceptional. It's not the love for your child—love is easy; it comes unconditionally for most parents. It's not the faith—my faith is shaken to the core every day. And it's not the caretaking—caring for any child comes with the territory. In the end, it's the strength to get up every single day and live this life through to the next day, one crisis at a time, even as many of us harbor the unique terror that we'll probably live to bury our children. It's about the ability to stand up and somehow deal with this, to work, to smile back at someone and say good morning, to understand humor and joy again, to live in a world where other parents, who just don't see the value of life, beat their children or leave them on doorsteps. All these things are exceptional to me now. All take conscious effort every day.

You do not have to accept this life with thanks and praise, but you do have to live it. The innocent child you created needs you to live it. For most of us, the pain and anger will not decrease with time. It will become a permanent part of us. It will destroy some of us; I've seen it destroy individuals, families, relationships and marriages. For those of us who survive, this pain only moves within us, from the front of our minds to the back, where it lives and lies dormant like a dark shadow of ourselves.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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Just stay aware of the pain and don't feel negatively about yourself when it creeps up on you. It happens to the best of us now and then. You'll look in the mirror and find yourself staring into something dark, behind your own eyes, and you'll recognize it as pain. It's just under the surface, all of a sudden, as strong and real as you are.

Don't be afraid of it—pain is life. Too often, it's a large part of it. You need to allow yourself the freedom to acknowledge pain and vent it as it comes up. Others may find you jaded, distant, aloof or just plain different. You are. You exist on a level they cannot comprehend. It is a special plane of existence—you know when you meet someone else on that plane. It's in their eyes, and no words are necessary. It's in the eyes of every parent I've ever seen walking the halls of hospitals and emergency rooms. For me, it helps to remember that there's only one place that's free from pain and, thankfully, I'm not there yet.

Some of us try to attach some spiritual purpose to what we go through with our sick children. From the day Reese was born until now—he turned three this year—my wife and I have tried to remain open to understanding our situation We have tried to find some good in it and we often do. Yet the bottom line is that we believe we will never understand why Reese has suffered so greatly for most of his three years. We have decided that if some greater purpose exists, its true meaning will elude us as long as we are in this life.

When I sit alone praying for my son, I sometimes pray with as much bitter confusion as faith. When I turn on the television because I can't sleep nights, I see children in Bosnia hit in rocket attacks, children in Africa starving to death, children all over the world suffering. At these moments, I have to stop myself from cursing what is good.

Life is good. Life is of God. I believe it is inherently negative to curse what is of God, so I do not allow myself to do that. But I do not pretend to understand this world either, and I cannot simply accept it with a smile. The trick is to maintain faith that chaos is not the norm in the spiritual realm, though it is often all we can see from the earth. **EP**

James Elliot lives in Pasadena, California with his wife, Marchelle, and son, Reese, 3. James, an actor, is writing his first screenplay. He also works as a property manager and bartender. Marchelle is a member of numerous early intervention committees and provides support to current NICU parents. Reese will soon begin attending a four-day-a-week special education preschool program. His favorite activity is music; he loves to hum and clap along with his favorite songs.

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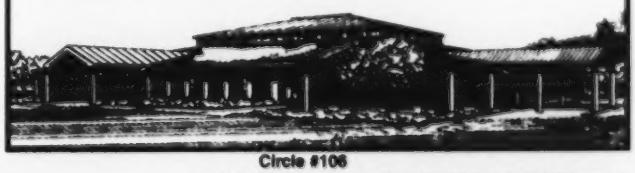

Circle #106

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ASK THE DOCTOR

by David Hirsch, M.D.

Atlantoaxial Instability

Q My 10-year-old daughter has Down syndrome. She wants to participate in some of the track and field events in the Special Olympics. Before she can participate, her doctor needs to fill out a physical examination form. The form requests the results of a special x-ray to rule out "atlantoaxial instability," which I understand is more common in children with Down syndrome. My daughter has never had this type of x-ray before. She plays very hard and has always been very healthy. Her physical examinations have always been normal; she has had no abnormal physical findings or complaints.

What is atlantoaxial instability? Is this something I need to worry about? What are the symptoms of this condition? How often should my daughter be x-rayed? Are track and field activities safe for her?

A There is some disagreement between physicians and various medical organizations about the diagnosis and treatment of atlantoaxial instability. Nor does everyone agree about its implications for individuals with Down syndrome who wish to participate in athletic activities. In answering this question, I will try to give my assessment of this currently controversial situation.

Atlantoaxial instability (AAI), also referred to as atlantoaxial subluxation, is a condition where there is increased mobility or movement between the first and second cervical vertebrae (segments of the spine in the neck). Various studies have estimated that this condition occurs in 10 to 40 percent of children with Down syndrome; 15 percent is probably most accurate. AAI is also found in some individuals with rheumatoid arthritis, abnormalities of the second cervical vertebrae or dwarfism.

AAI is usually diagnosed with x-rays of the cervical spine, but typically does not produce noticeable symptoms. Symptoms are usually seen only when subluxation (incomplete or partial dislocation) of the joint between the first and second cervical vertebrae leads to injury of the spinal cord in the neck. An individual with this type of injury may tire easily or may have difficulty walking. Other symptoms might include neck pain, limited neck mobility, head tilt, clumsiness, sensory deficits (numbness or weakness in the arms or legs) and spasticity (abnormally increased muscle tone).

Individuals with AAI who experience trauma or severe injury to the spinal cord usually exhibit these symptoms *prior* to the traumatic injury. That is, trauma or injury rarely causes the initial appearance or progression of these symptoms. Fortunately, individuals with Down syndrome who have AAI, as disagnosed through abnormal x-rays, rarely show any observable symptoms.

However, the situation is hardly that straightforward. In some cases, individuals with Down syndrome who are asymptomatic (have no symptoms), and who initially have normal x-rays of the cervical spine, will have abnormal x-rays later on, typically within the next three to six years. Other asymptomatic individuals with initially abnormal x-rays will have normal x-rays later, usually within the next six years. In fact, this type of change (from abnormal to normal) seems to be more common.

Asymptomatic AAI, while common in individuals with Down syndrome, does not seem to be a significant risk factor for later development of symptomatic AAI. According to the American Academy of Pediatrics Committee on Sports Medicine and Fitness, x-rays of the neck may have some value, but they have not been proven entirely effective for identifying individuals who are at risk of developing spinal cord injury while participating in athletic activities. The Committee concluded that it is more important to identify those individuals who have symptoms that indicate the possibility of spinal cord injury resulting from AAI. That is, it may be of more value to find those individuals who have early symptoms of spinal cord injury—before it leads to more serious medical problems—than to do routine x-ray screening of *all* individuals with Down syndrome.

The best way to identify symptomatic individuals is through regular, routine physical examinations, especially prior to participation in sports. It is also important for parents to learn the early symptoms of spinal cord injury resulting from AAI. This will enable parents who observe such symptoms to obtain immediate medical attention for their child. Doctors may order x-rays of the cervical spine or, on occasion, CAT scans or MRIs to further evaluate symptomatic individuals.

It does not sound as if your daughter has any symptoms of spinal cord injury resulting from AAI. Assuming her physical examination is otherwise normal, track and

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications should not be construed as an endorsement by Dr. Hirsch or EXCEPTIONAL PARENT of any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 308, Brookline, MA 02146-5005, (617) 730-5748 (fax).

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field should be a safe activity for her. For now, because it is required for participation in the Special Olympics, I would suggest that your daughter get an x-ray of her cervical spine to check for any abnormalities that might suggest AAI. The x-ray should not need to be repeated until your daughter reaches puberty, in three to five years, unless she develops any of the symptoms mentioned above.

Finally, although this is not an issue that affects your daughter now, if she is ever to have surgery involving her head or neck, many anesthesiologists and surgeons would recommend a pre-surgical cervical spine x-ray. If this screening detected AAI, doctors would take special care in positioning and manipulating her neck during the surgery.

More information on AAI may be obtained from The National Down Syndrome Society (666 Broadway, 8th Fl., New York, NY 10012; 800/221-4602; 212/460-9330; 212/979-2873, fax) and the Canadian Down Syndrome Society (811 14th St. NW, Calgary, AB, Canada T2N 2A4; 403/270-8500; 403/270-8291, fax). **EP**

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HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Health Insurance Covers Only One Wheelchair

Q Our health insurance plan allows for only one wheelchair per client, per lifetime. My child received a wheelchair at the age of four. When he was seven, we had to have the wheelchair adjusted at a cost of $1,400. The insurance company denied the claim because they do not "repair, replace or adjust equipment." We are not eligible for California Children's Services (CCS)* because of our family income, so we paid for the adjustment ourselves.

We will eventually need at least one additional chair. Is there anything I can do to reverse the insurance company's policy of one wheelchair per client?

A This is the first time I've heard of an insurance policy that restricts its coverage of durable medical equipment to the purchase of one wheelchair.

Some insurance policies may exclude coverage for specific types of durable medical equipment. However, if an insurance policy provides coverage for such equipment, the policy usually allows for the purchase of new equipment when necessary to meet a person's changing needs. Since a child with a mobility-related disability is likely to need either a new wheelchair or an adjustment to his current wheelchair as he grows, the kind of restriction you describe clearly presents a serious economic problem.

The obvious solution is to try to find a new insurance plan that does not include such a restriction. If you are able to locate a new insurance plan, try to make sure it will cover your child's medical needs immediately. Unfortunately, many plans have waiting periods for "pre-existing conditions"—medical conditions already present before the purchase of the policy—and some plans never cover pre-existing conditions at all. Plans with pre-existing condition clauses often have waiting periods that range from six months to a year. If your new policy has a waiting period, ask your child's clinical team whether a local children's hospital may be able to loan out equipment temporarily, or whether you could rent appropriate equipment.

If you cannot find a new plan, you can explore several other options. First, your child's public school system may be willing to pay for a new wheelchair if it relates directly to his educational needs—if, for instance, there is no other way for your child to get from classroom to classroom. You would need to be certain that the need for the wheelchair is noted in your child's IEP (Individualized Educational Plan). You would also need to raise the issue of whether your child could bring the wheelchair home—equipment specified in the IEP to be purchased by a school system must sometimes stay in school, although rules vary from school district to school district. The school's IEP team can review its current rules with you.

Second, local charitable organizations, such as church groups and fraternal organizations, may help pay for medical equipment for a child with a disability. You might want to contact such community organizations, your clergy person or a family service agency in your area for assistance.

You might also search for a used wheelchair that meets your child's needs. Many people who have children with disabilities may be interested in selling or exchanging wheelchairs.

In addition, many people with wheelchairs they no longer need may be interested in donating those chairs. Many people who use wheelchairs, for example, are fully covered by their insurers for the purchase of replacement chairs. In such cases, an individual may eventually end up with two or three wheelchairs, since insurance companies generally do not want used medical equipment returned.

Unfortunately, I don't know of any national program that makes used wheelchairs available at this point. The idea certainly makes sense, however, and could be extended to other medical equipment, as well.

You might want to consider getting in touch with a parents' group to see if they are interested in creating a program for exchanging used wheelchairs and other medical equipment. You may also want to consider establishing such a program on your own. The American Self-Help Clearinghouse (Northwest Covenant Medical Center, Denville, NJ 07834-2995, 201/625-7101, voice; 201/625-9053, TTY; 201/625-8848, fax) has experience helping people set up support groups and has indicated their willingness to work with interested people to establish a nationwide equipment exchange program. **EP**

** California Children's Services is a Children with Special Health Care Needs (CSHCN) program funded through federal monies (Title V of the Social Security Act) and matching state dollars. Currently, each state decides how CSHCN funds are spent, and services vary from state to state.*

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Networking

Information from The National Parent Network on Disabilities

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Executive Director

NPND Holds Annual Meeting

(left to right) Patricia McGill Smith, NPND Executive Director; Justin Dart, disability advocate; and Gene Michaels, inspirational humorist and NPND Annual Meeting keynote speaker.

From September 30 to October 2, 1995, NPND held its annual meeting at the St. James Hotel and in the halls of Congress in Washington, DC. One hundred parent leaders from across the country attended the meeting.

Representative Cunningham Receives NPND Public Service Award

Members of the NPND Board of Directors met with Representative Randy "Duke" Cunningham (R-CA), Chairman of the Early Childhood, Youth and Families Subcommittee of the House Committee on Economic and Educational Opportunities, which has been responsible for initiating the development of the reauthorization of the Individuals with Disabilities Education Act (IDEA). At the conclusion of the meeting, Joanne Butts, NPND president, presented Representative Cunningham with the NPND Award for Distinguished Public Service.

Health Care

Jack Ebeler, soon to be confirmed Deputy Secretary of Health, U.S. Department of Health and Human Services, spoke about proposed cuts to Medicaid and Medicare. These cuts, Ebeler explained, would render the programs incapable of meeting the needs of people with disabilities and senior citizens.

NPND Elects New Board Members

NPND has elected six new Board members. They are:

- Nancy Diehl, STEP (Support and Training for Exceptional Parents), Greeneville, Tennessee
- Bonnie Johnson, Arkansas Disability Coalition, Little Rock, Arkansas
- Debra Johnson, Idaho Parents Unlimited, Boise, Idaho
- Peggy LeBlanc, Project PROMPT, Metairie, Louisiana
- Janet Lonsdale, Parents Union for Public Schools, Philadelphia, Pennsylvania
- Denise Neal, Arc of Georgia, East Point, Georgia

Marty Ford of The Arc, Christina Metzler of the American Occupational Therapy Association and Barbara Huff of the Federation of Families for Children's Mental Health, expanded on that discussion, addressing a wide range of issues including Medicaid/Medicare and mental health legislation.

The Istook Amendment

David F. Arons of the Independent Sector, an organization that lobbies on behalf of non-profit organizations, explained the details of the Istook budget amendment, which is designed to limit the "political activities" of non-profit organizations and would prohibit them from providing *any* information about public policy or legislation. This amendment would severely limit the ability of PTIs (Parent, Training and Information centers) to inform parents about legislation affecting the educational rights of children with disabilities.

Reauthorization of the IDEA

A panel of staff members from the House Subcommittee on Early Childhood, Youth and Families and the Senate Subcommittee on Disability Policy updated meeting participants on the status of the IDEA reauthorization in both the House and the Senate. Both House and Senate planned on producing a draft of the bill before the end of October. *(Editor's Note: The House issued their draft of the bill on October 30, and the Senate anticipates releasing their draft on November 20. Parents need to be informed and involved. For information about drafts of these bills, contact your local PTI; NPND can direct you to that PTI if you do not know how to find it.)*

(left to right) Carol Blanton, Special Education Action Committee, Alabama; Connie Hawkins, Exceptional Children's Assistance Center, North Carolina, and retiring NPND Board member; and Martha Ziegler, TAPP (Technical Assistance for Parents Programs), Boston, Massachusetts.

The Role of Parents

Judy Heumann, Assistant Secretary of the Office of Special Education and Rehabilitation Services (OSERS); Tom Hehir, Director of the Office of Special Education Programs (OSEP); and Bob Williams, Commissioner of the Administration on Developmental Disabilities, U.S. Department of

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Circle #77

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Health and Human Services, called for a renewed commitment from parents to continue working for the educational rights of their children. NPND staff members Patricia McGill Smith, Executive Director, and Larry Searcy, Associate Executive Director, asked participants to evaluate the interest and energy of parents in their local communities for this type of active advocacy. NPND hopes to use this feedback to shape its strategies for the future.

The discipline issue

NPND briefed key Senate and House staff members on their concerns about the reauthorization of the IDEA. Senator Bill Frist (R-TN), Chairman of the Senate Subcommittee on Disability Policy, opened the briefing. (For the full text of his remarks, see "The Reauthorization of the IDEA," p. 46) After his remarks, NPND presented Senator Frist with its Award for Distinguished Public Service.

A panel of parents then met with Congressional staff members to voice concerns about the potential effects of discipline proposals now under consideration. Pat Morrissey, Majority Staff Director of the Senate Subcommittee on Disability Policy, and Robert Silverstein, Minority Staff Director, joined the panel to discuss the process of trying to reach a consensus about the discipline issue.

The discussion focused on proposed changes to the current "stay-put" doctrine of the IDEA. Currently, in the case of a disagreement between parent and school district, a student can remain in his or her current placement while due process runs its course. The House proposal would assure that once parents opt to exercise their Constitutional rights to due process, their children would be "put out" of regular placements and put into alternative placements while due process ran its course.

Once the House and the Senate have both passed their own drafts, a conference committee, consisting of members of both branches of Congress, will meet to come up with a single version of the bill to be presented again to Congress and then to the President. Our best estimate is that this bill will be on the President's desk within the next 60 days.

To make your opinions heard, contact Representative Cunningham, Chairman of the Early Childhood, Youth and Families Subcommittee (2181 Rayburn House Office Bldg., Independence Ave. and S. Capitol St. SW, Washington DC 20515); Senator Frist, Chairman of the Senate Subcommittee on Disability Policy (Senate Dirksen Office Bldg., Rm 422, 1st and C Sts. NE, Washington, DC 20510); Senator Nancy Kassebaum (R-KS), Chairperson of the Senate Labor and Human Resources Committee (Senate Dirksen Office Bldg., Rm. 428); and Representative William Goodling (R-PA), Chairman of the Economic and Educational Opportunities Committee (2181 Rayburn House Office Bldg.).

"My family does revolution"

Disability advocate Justin Dart called for people with disabilities and their families to pull together across organizations, ages, disabilities, political parties and other narrow interests to build a "revolution of rights." "Some families have hobbies, and some families do sports together," he explained. "*My* family does revolution."

Awards

NPND presented awards to Paula Goldberg and Connie Hawkins, outgoing NPND Board members, for their years of distinguished service to children with disabilities and their families. NPND also honored Gunnar Dybwad, Professor Emeritus of Human Development at Brandeis University, for his leadership in the field of disability rights throughout the world.

(left to right) Sue Pratt, CAUSE, Michigan; Paula Goldberg, PACER Center, Minnesota and retiring NPND Board member; and Judith Raskin, Parent Information Center, New Hampshire.

1073

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EXCEPTIONAL PARENT

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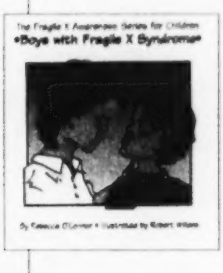
Publications



• *Boys With Fragile X Syndrome* is a children's book designed to educate peers, classmates and siblings about the characteristics of fragile X syndrome. The book is the first in a planned series and can be ordered from the National Fragile X Foundation, 1441 York St., Ste. 303, Denver, CO 80206; (800) 688-8765. Cost is $10, includes shipping and handling.

• *Welcome to God's World* is a free publication from the National Apostolate For People With Mental Retardation (NAPMR) that focuses on the initial concerns of parents after their children have been diagnosed with a disability. The booklet offers parents information about mental retardation, its impact on the family and a listing of resources. Contact NAPMR, 4516 30th St. NW, Washington, DC 20008; (800) 736-1280.

• *Planning Your Dreams: A Roadmap for Life After High School for Students with Disabilities and Their Families* is a guide that offers parents and students ideas to begin planning for life after high school. The publication focuses on Minnesota but also has useful information for students living in other states. Contact Minnesota Educational Services, 70 County Rd. B2 West, Little Canada, MN 55117; (612) 483-4442. Cost is $4.50 ($4 for MN residents), includes shipping and handling.

• *The 1995 Directory of National Organizations of and for Deaf and Hard of Hearing People* identifies 68 national consumer, service and professional organizations serving people who are deaf or hard of hearing. This free guide can be ordered from the National Information Center on Deafness, Gallaudet University, 800 Florida Ave. NE, Washington, DC 20002-3695; (202) 651-5051 (voice); (202) 651-5052 (TTY).

• *Answering Your Questions About Spina Bifida* is a comprehensive guide covering many medical and non-medical issues for parents and children with spina bifida. Contact Spina Bifida Program, Children's National Medical Center, 111 Michigan Ave. NW, Washington, DC 20010; (202) 884-3092. Cost is $4, includes shipping and handling.

Infant Studies Conference

The International Society for Infant Studies will hold its biennial conference April 18–21, 1996 at the new Westin Hotel in Providence, Rhode Island. Special workshops will be held on April 18, including one sponsored by the University of Miami Touch Research Institute, and another by the Boston Institute for the Development of Infants and Parents. For more information, contact Prof. Lewis P. Lipsitt, Dept. of Psychology, Brown University, Providence, RI 02912; (401) 863-2332; (401) 863-1300 (fax).

Needed: Air Travel Stories

Access to the Skies, a program of the Paralysis Society of America (PSA), wants to hear from travelers with disabilities about their air travel experiences. They are collecting information to find out how well airlines and airports are complying with the Air Carrier Access Act by accommodating travelers with disabilities. If you have flown recently or plan to fly soon, call PSA at (800) 643-8245, 8–4:30 (central time), Monday through Friday, or participate in the survey 24 hours a day by visiting their Internet web site at http://computek.net:80/access95.

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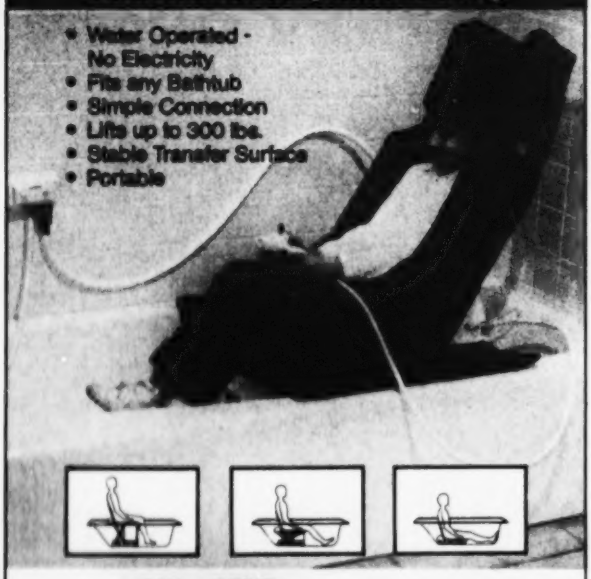
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Circle #180

1079

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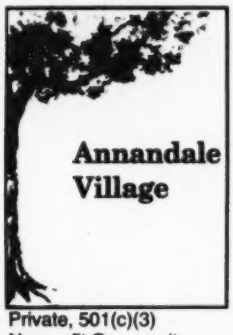

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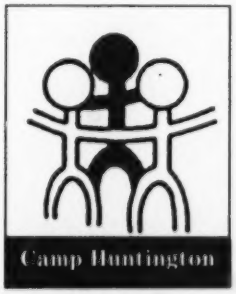

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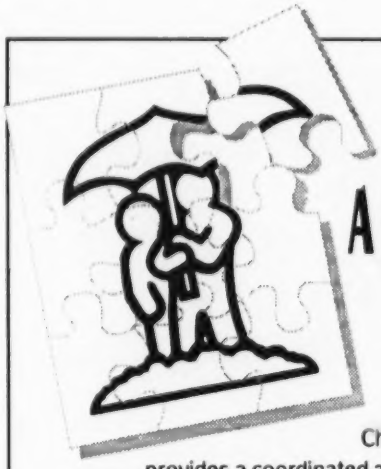

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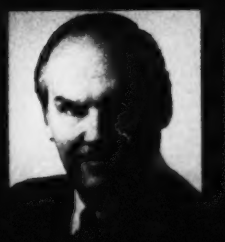

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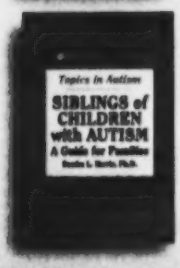

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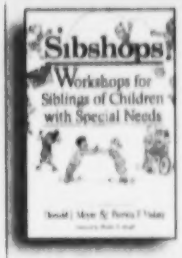

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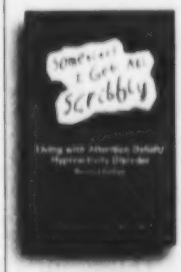

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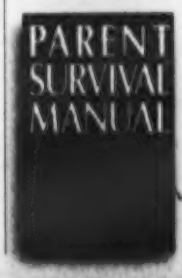

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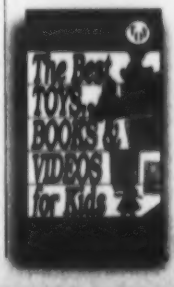

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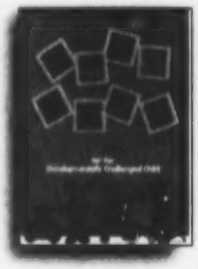

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Christopher and Patrick share a joke. Chris says he loves to make his brother laugh.

My name is Christopher Brown and I am nine years old. I have a brother named Patrick, who has bright red hair and is 17 years old. Patrick likes to watch TV, listen to music, dance and play games with me. He can't run very well, but he walks fast. He has trouble talking, but he has a great smile. He has a disability called cri-du-chat syndrome.

When we go out into the community, people stare at Patrick because he sometimes acts differently. This makes me feel sad because he is a really neat brother. I admit that he sometimes gets on my nerves, and I wish he didn't have to act the way he does. But Patrick is a very sensitive brother—he knows when people are looking at him strangely and making fun of him.

I wish everyone would love my brother like I love him. I wish all other kids would like him also. People need to be taught how to act with others who are different from them. We need to teach others that people with disabilities are good people, too. If each of us would just show one other person that people with disabilities have many *abilities*, what a great world this could be. **EP**

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'Twas the season! Eleven-year-old Patrick and three-year-old Christopher celebrated Christmas together in 1989.

Christopher, 9, lives with his parents, Patricia and Dewey, and his brother, Patrick, 17, in Richmond, Virginia. Patrick has cri-du-chat syndrome, a chromosomal disorder involving a deletion of the short arm of the fifth chromosome (5p-).

Christopher wrote this piece in response to an invitation from one of Patrick's case workers to express some of his concerns about his brother. Christopher is in the fourth grade at Fisher Model School in Richmond. He enjoys computer games, TV and soccer.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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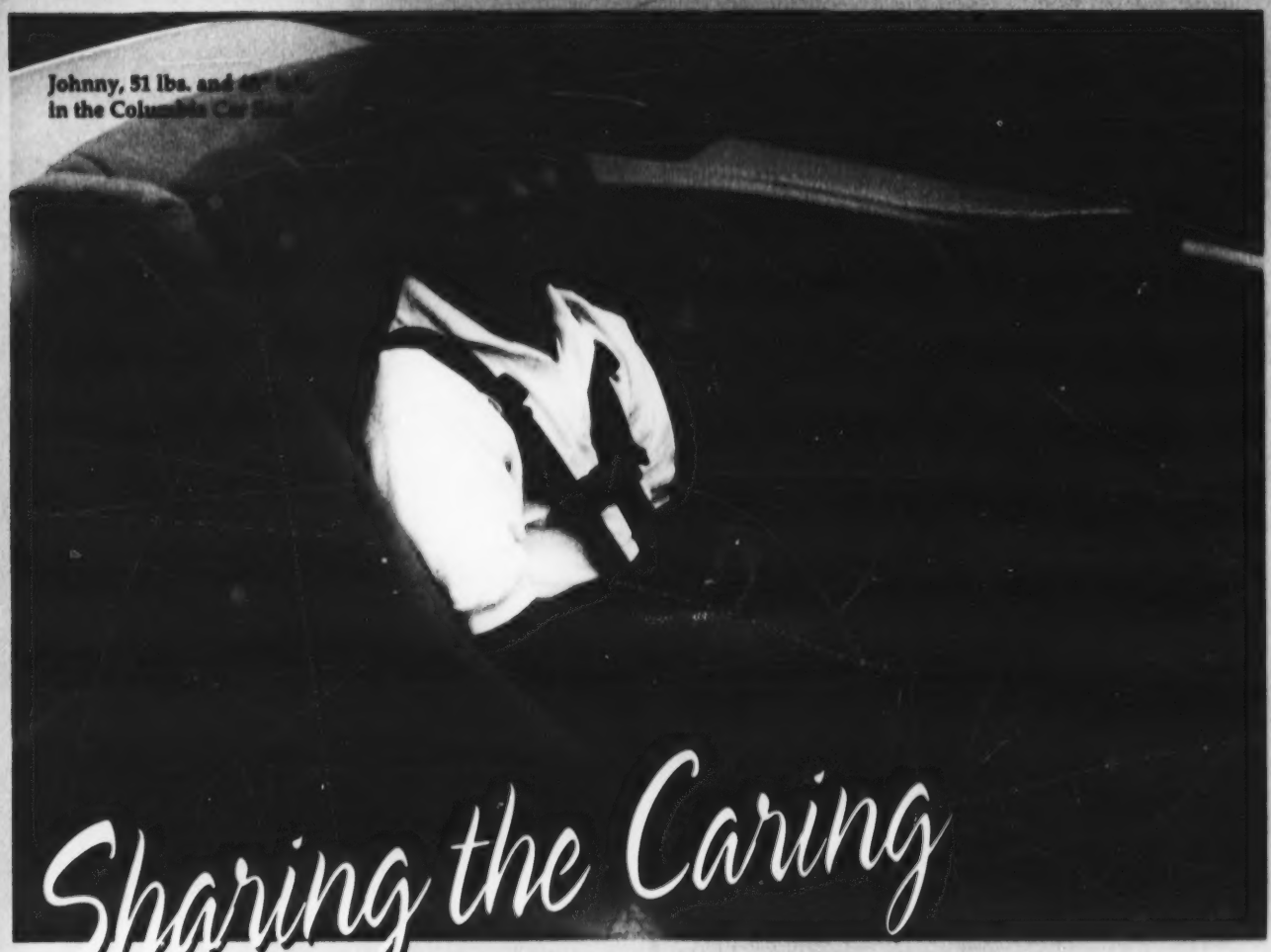

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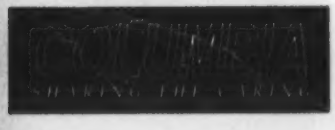

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